

POLIO NSW INC

formerly Post-Polio Network (NSW) Inc

NETWORK NEWS

Incorporating – **Polio Oz News**

Editors: Nola Buck and Susan Ellis
Email: editor@polionsw.org.au
Website: www.polionsw.org.au

PO Box 2799, North Parramatta
NSW AUSTRALIA 1750
Phone No: (02) 9890 0946

Patron: Professor Emeritus Sir Gustav Nossal AC CBE FAA FRS

President's Corner

Gillian Thomas

This brief bonus issue of *Network News* brings you an update from our recent Annual General Meeting and Seminar, together with details of a series of Clinical Practice Workshops being held for health professionals in northern metropolitan Sydney (page 2), and the latest news about the 2016 Australasia-Pacific Post-Polio Conference (page 3). This extra issue also gives us the opportunity to include the December 2015 (Summer Edition) *Polio Oz News* which is hot off the presses.

First, at our 27th AGM held on 5 December 2015 the following members were elected to the Management Committee:

Gillian Thomas	<i>President</i>
Susan Ellis	<i>Vice-President</i>
Merle Thompson	<i>Secretary</i>
Alan Cameron	<i>Treasurer</i>
Charles Anderson	
Anne Buchanan	

Nola Buck
Madeline Coelho
Ella Gaffney
Anne O'Halloran
Alice Smart
John Tierney

All existing Committee members re-stood for another term. The casual vacancy that we had carried since the 2014 AGM was filled when member Madeline Coelho generously put herself forward. Madeline has not previously served on the Committee but when we opened our Northcott office she volunteered her professional librarian skills which were of great benefit at that time.

Following the AGM and a light lunch, more than 50 members and friends enjoyed two very informative talks centring on *The New Assessment Clinic for Polio Survivors at Mt Wilga*. We first heard from Dr Helen Mackie (Consultant in Rehabilitation Medicine and Medical Director of the Clinic) who spoke about the Clinic's multi-disciplinary approach to assessment which provides to the attendees and their referring GPs information and options for further investigation, therapy and services. Nadege van Drempt (one of the Occupational Therapists who undertakes assessments at the Clinic) gave the second presentation which particularly focused on tips for avoiding falls. Be sure to look in the next issue of *Network News* for Sue Ellis' usual comprehensive Seminar Report.

That's it for this year – the only thing left to do is to wish you all ...

Merry Christmas and a Happy New Year



*The Management Committee
wishes each and every member
and your families
a joyous Christmas
and a healthy New Year*

Polio Australia-Rotary Partnership - Clinical Practice Workshops

Polio Australia is very pleased to be partnering with Rotary District 9685 to bring this series of FREE clinical practice workshops to allied health professionals wishing to learn more about management of the late effects of polio (LEoP). The workshops are driven by best-practice research from Europe and the USA and are open to all health and allied-health professionals. Although there are many cross-overs in the treatment and management of other chronic diseases and LEoP, there are also some very significant differences, which is why these workshops are so important. If LEoP is not identified, polio survivors can experience rapidly worsening symptoms due to inadvertently incorrect care.

Rotary District 9685 is one of two districts covering the Sydney metropolitan area. Its boundaries stretch from the Blue Mountains to the sea (north of Sydney Harbour), reaching across the Hawkesbury River, and north to Toukley on the Central Coast. Within its boundaries are the business districts of North Sydney, Chatswood, Gosford, Penrith, and the Ryde industrial area. The complete workshop series targets all these areas.

2016 Workshop Dates and Venues *(check the Polio Health website for late changes)*

Katoomba Saturday, **6 February 2016** : 9:30 am – 12:30 pm
Blue Mountains District ANZAC Memorial Hospital, Great Western Hwy and Woodlands Rd

Wyong Saturday, **27 February 2016** : 9:30 am – 12:30 pm
Wyong Golf Course, 319 Pacific Highway

North Rocks Thursday, **10 March 2016** : 9:30 am – 12:30 pm
Forsight Foundation, 241 North Rocks Road

Penrith Thursday, **24 March 2016** : 1:00 pm – 4:00 pm
Penrith RSL Club, 8 Tindale Street

Hornsby Thursday, **7 April 2016** : 1:00 pm – 4:00 pm
Mt Wilga Private Hospital, 66 Rosamond Street

Windsor Saturday, **16 April 2016** : 9:30 am – 12:30 pm
Hawkesbury District Hospital, 2 Day Street

Gosford Thursday, **28 April 2016** : 1:00 pm – 4:00 pm
Venue TBA

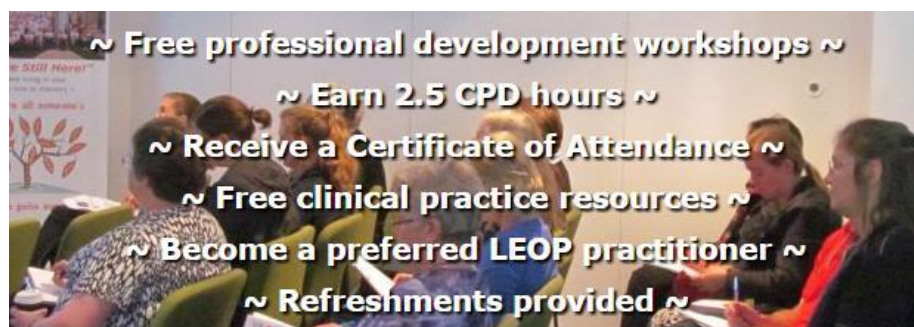
Narrabeen Thursday, **5 May 2016** : 1:00 pm – 4:00 pm
The Tramshed Hall, 1395a Pittwater Road

Who Should Attend?

Allied and other health practitioners such as: physiotherapists, occupational therapists, orthotists, exercise physiologists, nurses, podiatrists, speech pathologists, dietitians, social workers, case managers, and anyone else who is interested in knowing more about the post-polio body.

How Can You Help?

If you live within Rotary District 9685 and are consulting any health professionals in your local area, please be sure to let them know about the workshops and encourage them to register to attend.



For up-to-the-minute date, time and venue information, and for FREE registration, please ask your health professionals to visit the Polio Health website (see below)

For more information, visit: www.poliohealth.org.au/workshops

2016 Australasia-Pacific Post-Polio Conference

The **preliminary Conference Program** for the **Polio: Life Stage Matters** Conference being staged by Polio Australia in Sydney on **20-22 September 2016** is now online! You can download a copy of the Program from the Conference website (www.postpolioconference.org.au) or, if you don't have internet access, phone the Polio NSW office and a copy will be mailed to you. Registrations are now open and we urge you to register as soon as possible to ensure the Conference has sufficient delegates to proceed. **For any registration queries, please contact the Conference Planner, Interpoint Events, on 1300 789 845 or 02 8586 6115, or email <melanie@intermedia.com.au>.**

Registration Options <i>(the Early Bird rate is valid until Friday, 12 August 2016)</i>	Early Bird Rate excludes GST	Regular Rate excludes GST
3 Day Conference <i>includes complimentary invitation to the Welcome Cocktail Party</i>	\$1,200	\$1,320
3 Day Conference (Carer) <i>includes complimentary invitation to the Welcome Cocktail Party</i>	–	\$375
3 Day Conference (Polio Survivor, Family, Friend, Student) <i>includes complimentary invitation to the Welcome Cocktail Party</i>	\$540	\$600
2 Day Conference	\$900	\$990
2 Day Conference (Carer)	–	\$250
2 Day Conference (Polio Survivor, Family, Friend, Student)	\$405	\$450
1 Day Conference	\$500	\$550
1 Day Conference (Carer)	–	\$180
1 Day Conference (Polio Survivor, Family, Friend, Student)	\$225	\$250
Gala Dinner Ticket (Wednesday 21st September 2016)	–	\$100

Note: Delegates not attending the 3-day Conference can register for the Welcome Cocktail Party at \$50 + GST per person.

Any delegates registering as a "Carer" should meet one of the following criteria in order to qualify: you receive a Carer Payment, or you are a Registered Attendant Carer (professional, paid position).

Description: Personal Assistance Carers work in private homes or care facilities to help clients with common tasks, such as bathing, dressing, grooming and using toilet facilities. Most personal care assistants work for private clients, home health providers or agencies that offer services to senior citizens and the disabled.

The 'Carer' category only applies if the delegate requires the above mentioned level of personal assistance. Companions of independent delegates are considered 'Family' or 'Friend'.

Delegate cancellations received in writing by 19 August 2016 will incur a \$100 cancellation fee. Cancellations received after 19 August 2016 will receive NO refund. A replacement delegate can attend with no penalty charge but must be advised to the Conference Planner

The Conference will be held at the **Four Seasons Hotel**, a five-star luxury hotel in Sydney's CBD, located at 199 George Street Sydney NSW. **The Four Seasons has a special rate for delegates of the Post-Polio Conference – \$265 per room per night (incl. GST), and \$35 per person for breakfast.** To book this accommodation, ring the Four Seasons on 02 9250 3100, or visit the Accommodation page on the Conference website for online options. **To get the above rates, please quote the code PPCO1016 when booking.**



Volume 5, Issue 4



Polio Oz News

December 2015—Summer Edition

Polio: It's Not Over Till It's Over!



Federal Members and Senators 'Walk' in support of Australia's 400,000 Polio Survivors

While it is only a short walk for some, it's a real challenge for others. *Walk With Me* is an annual event that challenges us all to take the time to walk alongside people with disabilities.

This year, Polio Australia's *Walk With Me* activity headed to Parliament House in Canberra to engage our nation's leaders in this awareness raising event! October was also National Polio Awareness Month, so when better to take Polio Australia's *Walk With Me* challenge?

Mark Coulton MP and Senator Rachel Siewert led bipartisan Members Catherine King MP, Dr David Gillespie MP, and 20 polio survivors and supporters in the *Walk With Me* event at Parliament House on the 15th October, at 1.00pm. People assembled in the Marble Hall and walked, wheeled, or scooted to either the Senate or the

House of Representatives front doors and back. A great way to recharge before heading in to Question Time!

"We're Still Here!" is the catchcry of Australia's single largest physical disability group – the survivors of Australia's polio epidemics.

Polio Australia's President, Dr John Tierney OAM, contracted polio at birth. *"Living with the Late Effects of Polio, I understand how the proper management of this condition can make such a difference to quality of life for others like me. At Polio Australia we have developed world class programs and resources to help polio survivors to manage their condition and be assisted by health professionals using clinical best practice. However, with our current level of resources we cannot provide this assistance on a large enough scale. As Polio Australia receives no government funding we need support for our fundraising efforts such as Walk with Me in Canberra to help more polio survivors in Australia."*, he said. 🌟

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

Polio Australia

Representing polio survivors
throughout Australia

Suite 119C, 89 High Street
Kew Victoria 3101
PO Box 500
Kew East Victoria 3102
Phone: +61 3 9016 7678
E-mail: office@polioaustralia.org.au
Website: www.polioaustralia.org.au

Contacts

President—John Tierney
john@polioaustralia.org.au

Vice President—Gillian Thomas
gillian@polioaustralia.org.au

Secretary—Jenny Jones
jenny@polioaustralia.org.au

Treasurer—Brett Howard
brett@polioaustralia.org.au

National Program Manager
Mary-ann Liethof
mary-ann@polioaustralia.org.au

From the President

*Dr John Tierney
President*



As 2015 draws to a close we are pleased to report that it has been another very successful year for Polio Australia with the development of new initiatives, resources, programs and partnerships. As usual this has been achieved with very few resources or people to do the work. My special thanks go particularly to Mary-ann Liethof and Gillian Thomas who continue to give their all to our vital work in support of Australia's 400,000 polio survivors.

To occupy her spare time this year, Gillian decided to revise our Polio Australia Constitution now that we have given it a seven year test run. One of the most exciting changes has been, with the Board's approval, the creation of three additional skills-based positions on the Board.

At the recent November AGM of Polio Australia, the Board unanimously approved the appointment of Fran Henke (Victoria) with the special responsibility of Communications Coordinator, and Sue Mackenzie (Queensland) with special responsibility for Fund Raising and Rotary Club liaison.

At the District level we continue to work with Rotary District 9685 which has provided \$20,000 dollars in funding and is now working closely with Polio Australia in the running of ten clinical practice workshops in their northern Sydney district.

ARC Health has already conducted two of the workshops and the training sessions for health professionals were very well received. The workshops will resume in February.

Polio Australia continues to widen and deepen our involvement with Rotary with the aim of developing a long-term partnership with this organisation, which will assist Australians with the Late Effects of Polio. We currently have a panel of 22 speakers to present at Rotary Clubs, and this program will now be managed by our most recently appointed Board member, Sue Mackenzie. If you would like to join our panel of speakers and receive our speaker's package please contact [Mary-ann](#). Donations from Rotary Clubs now make up 10% of Polio Australia's budget.

In late October 2015 we returned to the Canberra halls of power, but this time in addition to meeting with our Parliamentary Patrons we held a Walk with Me event and invited the members and senators to Walk with Us from the front entrance of Parliament House to either the Senate door or the House of Representative door and back.

We were joined on the Walk by six members and senators and a number of polio survivors. My special thanks go to Brian Wilson for bringing along his Canberra Support Group team. As you can see on the front page, we were all very prominent in the parliament wearing our "We're Still Here!" tee shirts. Financially the day was also very successful — we raised over \$6,000 dollars.

World Polio Day on 24th October 2015 closely followed our descent on Canberra and Mary-ann and I were invited to speak at a well-attended and successful Polio Day organised by Polio Network Victoria. I also chaired a panel discussion on the NDIS at this event.

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From the Editor



Mary-ann Liethof
Editor

With the end of the year rapidly approaching **again** (*I'm sure this has been the quickest year EVER*), I have had to make time in my frantically busy schedule to reflect on what Polio Australia has achieved this year (page 6).

As always, I am amazed at the progress we have been able to make in our six years of active operations (*although Polio Australia was actually born in 2007*), considering we have had no increase in resources — staff or financial! In fact, the boost we had for the three years funding from The Balnaves Foundation ceased at the end of 2013, and has never been replaced. How do we do it? I certainly have no idea, as the business end of things is handled exceptionally well by the inaugural President, Gillian Thomas, now Vice President, and probono Business Manager and web guru.

Polio Australia held its Annual General Meeting in November, and our [Annual Report](#) provides a clear picture of what we've been doing and what we've had to do it with. Fascinating reading! Of course, it's all about *your* donations (page 10).

Of course, current President and National Patron, John Tierney, is a force to be reckoned with when it comes to lining up our lobbying visits to Canberra, and persuading people to sponsor him for the annual "Walk With Me" events. John is a

very 'hands-on' President, and we are incredibly fortunate to have the benefit of his experience, knowledge and ongoing pro-bono lobbying services (page 1).

We also have the benefit of a small number of dedicated volunteers who go the extra mile to fundraise on Polio Australia's behalf (page 9), speak at Rotary meetings, and provide support with administration, social networking, public relations, and more.

And I am very excited with the promise of things to come in the New Year: strengthening relations with Rotary International (pages 4 and 15); more Clinical Practice Workshops for health professionals (page 4); and the 2016 Australasia-Pacific Post-Polio Conference (page 7), where I will also be meeting up again with international friends and colleagues who I have met over the years.

So my reflections have revealed that I certainly have a lot to be thankful for, and many people to thank along the way. But isn't that what this time of year is all about? Giving thanks, and finding joy in purpose and giving to others? While there may still be much to 'fix' in both our personal lives and the wider world, I can heartily recommend making the time to think about all the good things as well. Oh, and remember to 'breathe'!

All the very best for the Season. 🌟



Mary-ann

From the President (cont'd from p2)

Probably the most exciting current development is the continued planning for our Australasia-Pacific Post-Polio Conference to be held over 3 days, 20th-22nd September 2016, in Sydney.

Please put the Conference 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.

[Registrations are now open](#) and it is important that you register as soon as possible as we need to reach a certain registration number by March 2016 for the Conference to proceed. I will be signing up before Christmas. How many of you can beat me to it!

Have a great Christmas and all the best for 2016. 🌟

John



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

**20-22
SEPTEMBER
2016**

**FOUR
SEASONS
HOTEL
SYDNEY**

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LEoP Clinical Practice Workshop Series Starts

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- ~ Receive a Certificate of Attendance
- ~ Free PDF of 100 page resource "Managing Muscles and Mobility", and more ...
- ~ Refreshments provided

The Late Effects of Polio FREE Clinical Practice Workshop Series

POLIO: IT'S NOT OVER

Decades after the poliomyelitis epidemics in Australia, the aftermath of the disease is now becoming evident in our ageing 'polio population'. An estimated 400,000 people may be suffering the Late Effects of Polio (LEoP) or Post-Polio Syndrome (PPS). Do you know how to recognise these conditions in your practice?

CHRONIC ILLNESS WITH A DIFFERENCE

There are many cross-overs in the treatment and management of other chronic diseases and LEoP/PPS, and there are also some very significant differences. If LEoP is not identified, the client can experience rapidly worsening symptoms due to inadvertently incorrect care.

YOU CAN IMPROVE THEIR FUTURE

For many LEoP/PPS clients, biomedical and pharmaceutical treatments have limited efficacy. Polio survivors are turning their attention and hopes to allied health practitioners to help them improve their quality of life, and prolong their daily functional ability as they age. With a holistic approach to care and increased awareness within the greater health sector, LEoP/PPS clients can manage their symptoms, live better, and age well.

Registration: www.poliohealth.org.au/workshops
Email: workshops@poliohealth.org.au

1	Ryde Royal Rehab 235 Morrison Rd	Thursday 26 November 2015 1.00 – 4.00pm
2	St Leonards ARC Health 3/41 Herbert St	Tuesday 8 December 2015 5.30 – 8.30pm
3	Katoomba Blue Mountains District ANZAC Memorial Hospital Great Western Hwy & Woodlands Rd	Saturday 6 February 2016 9.30am – 12.30pm
4	Wyong Wyong Golf Course 319 Pacific Hwy	Saturday 27 February 2016 9.30am – 12.30pm
5	North Rocks Forsight Foundation 241 North Rocks Rd	Thursday 10 March 2016 9.30am – 12.30pm

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Rotary District 9685
partnering with Polio Australia
to deliver

3 hour Workshop Topics

- ☐ **Why We Vaccinate:** a brief history of polio in Australia
- ☐ **What is polio?:** The pathophysiology of poliomyelitis
- ☐ **Demystifying Late Effects of Polio and Post-Polio Syndrome:** what's the difference?
- ☐ **The Aging Polio Population:** joining the dots of problems experienced in LEoP / PPS clients
- ☐ **"Did You Have Polio?":** identifying people who may be experiencing LEoP / PPS
- ☐ **Practical strategies** used by physiotherapists, orthotists, and various other allied health professionals to address key concerns such as managing pain and fatigue, and help with stability and avoiding falls
- ☐ **A Late Effects of Polio Case Study:** Q&A with local polio survivors and team care simulation

6	Penrith Penrith RSL Club 8 Tindale St	Thursday 24 March 2016 1.00 – 4.00pm
7	Hornsby Mt Wilga Private Hospital 66 Rosamond St	Thursday 7 April 2016 1.00 – 4.00pm
8	Windsor Hawkesbury District Hospital 2 Day St	Saturday 16 April 2016 9.30am – 12.30pm
9	Gosford TBA	Thursday 28 April 2016 1.00 – 4.00pm
10	Narrabeen The Tramshed Hall 1395a Pittwater Rd	Thursday 5 May 2016 1.00 – 4.00pm

Polio Australia
Representing polio survivors throughout Australia

Rotary
District 9685

The Polio Australia and Rotary District 9685 partnership project to run a pilot series of ten LEoP Clinical Practice Workshops in Sydney commenced at Royal Rehab in Ryde on the 26th of November with a dozen allied health professionals attending. This was followed by a second Workshop held at ARC Health in St Leonards on the 8th of December for 21 multi-disciplined health professionals.

Specialising in neurological conditions and rehabilitation, ARC Health is providing the training for the ten pilot Workshops. Neurophysiotherapist, Anna Jones, facilitated the Ryde Workshop, whilst the St Leonards Workshop was run by the ARC Health's Principal and Neurophysiotherapist, Melissa McConaghy. Melissa is also a member of Polio Australia's Clinical Advisory Group.

Rotary Club Members Bob Kaye-Smith from Ryde, Assistant Governor Noel Cislowski from Chatswood, and District Governor Gina Growden and Bob Aitken representing District 9685, all contributed to the planning and execution of these Workshops, for which Polio Australia is very grateful.

Polio NSW members Gillian Thomas, Susan Ellis and Rosemary Cantwell also attended the Workshops to provide participants with practical 'case study' Q&A opportunities.

eventually roll these Clinical Practice Workshops out, not only to other NSW Rotary Districts, but across Australia and New Zealand. The benefit to Australia's and New Zealand's thousands of polio survivors of being treated by 'informed' health professionals would be invaluable. However, the only way to do this effectively and efficiently, is for Polio Australia to employ its own physio/trainer and administrative assistant to run the program. As Polio Australia currently lacks the resources to do this, it is hoped that a successful pilot will encourage an adequate investment in delivering this vital and unique service.

To find out more about this Clinical Practice Workshop series, and to access a vast range of additional resources for health professionals, go to Polio Australia's 'Polio Health' website: www.poliohealth.org.au.

LEoP Clinical Practice Workshop Series *(cont'd from p4)*



Clockwise from top left: Gillian Thomas in Ryde Workshop case study session; Melissa McConaghy and Anna Jones (facilitators); St Leonard's Workshop; Susan Ellis, Rosemary Cantwell, Jennifer McConaghy (Admin), and Bob Aitken (Rotary)

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2015 At A Glance

January	Launched new website resource for health professionals: www.poliohealth.org.au
February	Received positive responses from dozens of national and international post-polio specialists to speak at the 2016 Australasia-Pacific Post-Polio Conference
March	Negotiations with 2016 Conference organisers relating to program and schedule updates
April	Promoted and finalised planning and preparations for the Polio Health and Wellness Retreat being run in Torquay, Victoria
May	Held 6th Polio Health and Wellness Retreat
June	First 2016 Conference Steering Committee Meeting
July	Discussions with International Post-Polio organisations regarding the 2016 Australasia-Pacific Post-Polio Conference
August	Presented to 1st Year Orthotics students at La Trobe University
September	Participated in "Walk With Me" fundraising event in Parramatta, NSW
October	Polio Awareness Month "We're Still Here!" Campaign and "Walk With Me" fundraising event in Canberra, ACT
November	Polio Australia's AGM and first pilot Late Effects of Polio: Clinical Practice Workshop held in Ryde, NSW
December	Second Clinical Practice Workshop held in St Leonards, NSW, and Australasia-Pacific Post-Polio Conference Preliminary Program uploaded to website

Polio Health Website

Polio Australia
Improving health outcomes for Australia's polio survivors

Select Language

Clinical Practice Workshops
BOOK NOW!

Have you visited
Polio Australia's
www.poliohealth.org.au
website yet?

This website is a valuable resource for health professionals and polio survivors alike. It provides information on our clinical practice workshops, the latest clinical research papers on a range of topics, videos of conference presentations by post-polio experts, and a portal where you can purchase and/or download Polio Australia's clinical practice publications.



First Regional Post-Polio Conference

By [Kymberly Martin](#)

Source: [Freedom2Live](#)—24 November 2015

Delegate registration is now open for the Australasia-Pacific Post-Polio Conference. The conference will be held in Sydney, September 20-22, 2016. Among the 24 keynote speakers for the inaugural event for the region are US rehabilitation physician William DeMayo; US Post-Polio Health International director, Joan Headley; president of the European Polio Union, John MacFarlane; and head of clinical research, National Centre for Immunisation Research & Surveillance Australia, Robert Booy.

The theme of the conference 'Polio – Life Stage Matters' will address the challenges and exchange knowledge about the diagnosis, treatment and management of the post-polio condition across different age groups. The three day conference will target professionals in rehabilitation medicine, allied health, nursing, neurology, orthopaedic surgery and virology. It is also bringing health care providers, researchers, polio survivors, caregivers and patient organisation representations from around the world.

The conference is being hosted by Polio Australia, the national body representing Australia's 400,000 polio survivors. Polio Australia is working towards standardising quality information and service provision across the country to ensure polio survivors have access to appropriate health care and the support required to maintain independence and make informed lifestyle choices.

However, because most polio survivors are over 65 they are ineligible to be part of the NDIS, which is the age when most will need more aids and equipment. Polio Australia president, Dr John Tierney, told F2L that even for the few who are under 65, having polio does not guarantee automatic entry into the NDIS. He said Polio Australia represents the largest physical disability group in the country but despite numerous representations to governments has been unable to get just recognition and proper services in place for polio survivors. *"Clearly budget implications have forestalled any changes to government policy and at the moment the only option is what is available from aged care but the cost of Home Care packages is increasing. We are advocating the government put more funding into aged care services particularly for programs to help people self-manage the disease. Polio survivors need to know what to do and what not to do when it comes managing their health."*

Tierney has also been adding voice to demands for a fulltime Disability Commissioner. This follows the recent announcement by Attorney General, Senator George Brandis, that Susan Ryan will continue as Disability Discrimination Commissioner in addition to her role as Age Discrimination Commissioner. Dr Tierney said with the complex services being brought in under the NDIS, those with disability deserve and will require full attention. *"Australia's post-polio community has survived, had gainful employment and contributed to society for many years despite their disability."*

He said ensuring equivalent services under aged care funding initiatives and the protection of a full time Disability Commissioner is only reasonable. *"If the office is not given the due weight and dignity of a fulltime person, we will never be heard."*

For more information and delegate registration visit: www.postpolioconference.org.au 🌐

2016 Australasia-Pacific Post-Polio Conference

Program

Planning for this Conference is well under way, and the Preliminary Program can now be viewed and downloaded from the website [here](#).

Call for Abstracts

A second and final call for abstracts for Session Three 'Free Papers' will close on 31st March 2016. If you would like to submit a paper, please download the [Abstract Guidelines](#) and [Abstract Template](#).

Presenters

In addition to a number of Australian health professionals, confirmed Presenters are bringing a broad range of knowledge, skills, and experience with them from countries including: Brazil, Denmark, India, Ireland, Italy, Japan, Pakistan, Spain, Sweden, The Netherlands, the UK, and the USA.

Registration

Register early for this unique and truly international Post-Polio Conference. 🌐

www.postpolioconference.org.au

Polio Awareness Month Activities



Panel Discussion: (L-R) Dr John Tierney, Dr Stephen de Graaff, Robyn Salt, Bev Watson, and Peter Willcocks

A splendid event – Victoria's Polio Day By Fran Henke

Polio Day 2015 [held on Saturday 24 October] was one of the best. How can we say that? Biggest turn out for some years – 100 registrations from all over Victoria; great buzz all day at the Springvale Town Hall; plenty of food; and an excellent program.

The event was opened by Gabrielle Williams, MP for Dandenong, Parliamentary Secretary for Carers and Volunteers. Ms Williams was representing the Premier, whose electorate we were in, as well as Martin Foley, Minister for Disability and Ageing.

Our theme was Making Sense of Change and Ms Williams assured us no-one would be disadvantaged by the introduction of the NDIS and changes to Aged Care Services. Aids and Equipment programs would continue to be funded, along with Polio Services Victoria at St Vincent's Hospital. Ms Williams reiterated the State Government's commitment to vaccination with its 'No Jab, No Play' policy.

A panel discussion 'Making Sense of Change' followed, moderated by Dr John Tierney OAM, patron of Polio Australia. Joining the discussion was Dr Stephen de Graaff, director of Pain Services, Senior Rehabilitation Physician at Epworth Healthcare; Bev Watson, Rural Access coordinator and Polio Reference Group chair; Robyn Salt, Aged and Disability Services manager, Moorabool Shire; and Peter Willcocks, co-convenor Bayside Polio, member Policy Council, Council on the Ageing.

Before lunch the Polio Australia team of Dr Tierney and National Program Manager Mary-ann Liethof talked about the successful work being done to improve Rotary International's understanding of polio survivors and the support needed. Polio Australia is conducting information programs for clinicians as well as making its clinical studies freely available. Mary-ann spoke about the 2016 Australasia-Pacific Post Polio Conference 'Life Stage Matters' to be held in Sydney in September. Chaired by Dr de Graaff, the conference has already attracted submissions from leading polio specialists from Europe and America. 🌐

World Polio Day: Brisbane 23 Oct 2015

The meeting rooms at Spinal Injuries Australia were filled to capacity for World Polio Day which was well attended by 56 members, guests and staff. Some attendees travelled from as far away as Rockhampton and Gayndah.

Dr Peter Nolan, renowned Post Polio specialist with over 30 years' experience, delivered a unique three part presentation of "A reflection of the mind body soul relationship of the journey with Polio." All participants were presented with a workbook produced by Dr Nolan. 🌐



Australia All Over By Ian McNamara

Source: ABC Radio—25 October, 2015

Saturday the 24th marked World Polio Day, and on Sunday Macca received a call from Christine in Fitzroy. In 1954 she and her sister contracted the disease whilst living in Rome.

Ian also replayed an interview which he recorded with author Kerry Highley, whose book 'Dancing In My Dreams' tells the story of Sister Kenny's pioneering work on a treatment for sufferers of polio.


Click [here](#) to listen to the interviews. 🌐

Fundraising-Bribie Island Style

World Polio Day was the perfect opportunity for a fundraising luncheon, organised by polio survivor, Bill Peacock, and the Rotary Club Bribie Island, with proceeds going to Polio Australia.

The 40 or so people who attended were given a scrumptious lunch at the Bribie Island Hotel, entertained by local vocalist, 'Kelsy', delighted by the Special Guest 'Gold Coast BENJI', and a lucky few left with a range of creative raffle prizes.

This fun day raised approximately \$1,700 towards Polio Australia's work. We are very grateful to Bill and his small team of volunteers, and the Rotary Club of Bribie Island for all their efforts! 🌈

 Polio Australia Representing polio survivors throughout Australia	
Not for Profit National Peak Body Celebrate Bribie Island Qld \$50 Per Head	Rotary Bribie Island Awareness Knowledge Information Supporting the survivors of Polio
World Polio Day Saturday 24th October 2015	
SPECIAL GUEST Gold Coast BENJI	ENTERTAINMENT The amazing soloist ONE VOICE "KELSY"
	
PRIZES Raffles Auction Bribie Island Hotel 29 Sylvan Beach Esplanade Bellara Qld 4507 Ph: 07 3408 7477	
 bribie island hotel	
Luncheon - Saturday 24th October 2015 12 noon to 3.30 pm	
Tickets available for \$50 each - phone Bill or Peter on 0403 686 998 Online tickets can be purchased by credit card at www.trybooking.com/IWSN Net proceeds donated to support the work of Polio Australia	



Dr Margaret Peel and BENJI



Checking out the Raffle prizes



(L-R) Peter Sheehan, Bill Peacock, Kelsy with BENJI, Sue Mackenzie



BENJI enthralled the guests!

Supporting Polio Australia

Polio Australia would like to thank the following individuals and organisations for their generous support from 1 August to 31 November 2015:

Hall of Fame

Name	Donation
Dr John & Pam Tierney	\$3,565
Jill Pickering	\$10,000
Total—\$13,565	

General Donations

Names				
Anonymous	Jill Burn	Barbara Burnett	Daisy Grist	Karin Kolenko
Joan & Graeme Smith	Zebra Rock Gallery	Lioness Club of Tamworth		
Total—\$3,337				

Activity Donations

Name	Donations
Walk With Me—NSW	\$1,870
Walk With Me—ACT	\$6,286
World Polio Day Luncheon	\$1,680
Total—\$9,836	

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 life 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 a number of methods. Click on the button 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. 🌐

Post-Polio In The News

Post-Polio Syndrome: Australia's Forgotten Disability By Norman Hermant

Source: abc.net.au—1 November 2015



Frances Henke contracted polio when she was two years old

The World Health Organisation declared Australia polio free in 2000. But the disease remains a threat in Africa, Afghanistan and Pakistan, which recorded its highest level of polio infections in a decade last year.

And in Australia, the disease is still very much with us.

It is estimated there are 400,000 Australian polio

survivors. Peak body Polio Australia says this makes them the single-largest physical disability group in the country.

From the 1930s to the 1960s, at times polio reached epidemic proportions in Australia. The virus attacks the motor neurons that relay messages from the spinal cord to muscles and can lead to muscular degeneration and, in some cases, paralysis.

Widespread use of the polio vaccine eventually halted its spread. But for thousands of polio survivors, the disease is not finished. Decades after they contracted polio, symptoms can return in the form of post-polio syndrome (PPS).

Advocates say they not only want to see more awareness of PPS, they also want those diagnosed to know what they are in for — and to reach out for help.

Dr Stephen de Graaff says PPS takes an especially high emotional toll, because polio survivors spend decades overcoming the effects of the disease to lead productive lives.

"When PPS hits, there is nothing they can do. We're in a situation where we're not going to be able to cure what happens", Dr de Graaff said. "We have to manage it."

Read the full article [here](#), or view on YouTube [here](#).

[New Zealand] Polio victims: 'Society's forgotten about us' By Ashleigh Stewart

Source: stuff.co.nz - 18 October 2015

Polio sufferers, misdiagnosed by young doctors with short memories, are now taking their campaign to Parliament. ASHLEIGH STEWART spent two months attending polio meetings, speaking to dozens of sufferers and interviewing experts.

It was a Wednesday like many before it. John Carver woke and immediately checked on his wife. Patricia Carver's long list of health issues had left her unrested and in pain again. She said she was tired and wanted to take something to help her nod off faster. Carver told his wife he would leave her to sleep.

While he was out, Patricia Carver called her neighbour to complain of her tiredness and spoke of taking some Valium. At about 10am she called her son in Australia and told him she loved him and "everyone else".

After suffering a suspected drug overdose, Patricia was rushed to hospital and spent six days in intensive care. With her condition seemingly improving, Patricia was taken off the ventilator and was being prepared for transfer to a ward.

But while Carver, his son and daughter-in-law were out for lunch that afternoon, Patricia went dramatically downhill. She died hours later with her family by her side.

Carver was devastated. He argued for years that a misdiagnosis of Parkinson's had led to his wife's depression, when in reality she had been suffering from post-polio syndrome.

Read full article [here](#).

Post-Polio In The News

Our man stands tall for his mob

Source: Sunshine Coast Daily—7 November 2015

Paul Constable-Calcott almost had to pinch himself when he gave a presentation to the United Nations in Geneva last year.

"I was just a kid from a tin shack on the banks of the Lane Cove River, and here I am in Geneva", he said.

Paul, 56, of Eudlo, was in Geneva to make a presentation about the incarceration of Aboriginal people with a disability.

He made the presentation on behalf of the First Peoples Disability Network, Australia's peak organisation for Aboriginal people with disabilities.

The 56-year-old had never pictured himself speaking at an international forum on behalf of his mob.

"I can't describe the pride", he said. *"And the responsibility."*

Paul's father was a Wiradjuri man and his mother was Irish.

At 18 months, Paul contracted polio, which left him with difficulties walking.

His father, aware that the little boy could be targeted for forcible removal, sometimes went into hiding for the sake of his family.

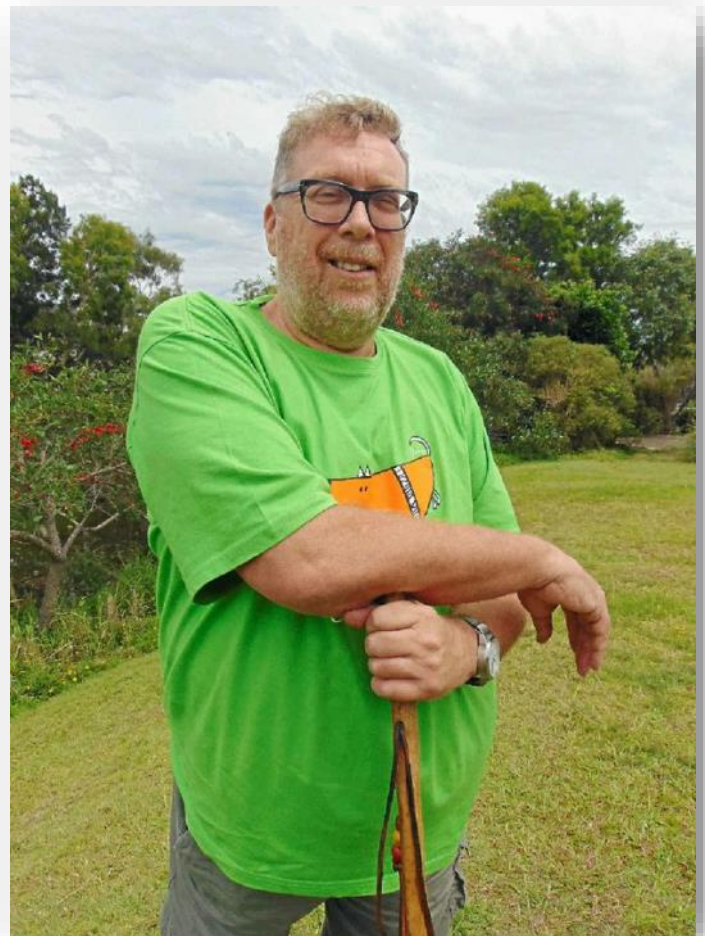
"My dad was always conscious of having a fair-skinned son with a disability, they'd take me away."

"When the social workers came around, dad was never around, so it was just my mum if they came to visit", he said.

Paul was still brought up to know his Aboriginality.

After school, he trained in horticulture in search of a connection with the land, but while working at a home for children with disabilities, switched course in life.

"It was all very new to me but I really loved working with kids with disabilities. I think having my own disability, there was a bit of a commonality there."



Besides the First Peoples Disability Network, Paul is involved these days in Suncare Community Services, Synapse Queensland, the Murri Disability Advisory Network, and the Nandjima art group.

His work sometimes involves providing cultural advice on disability services but is also about educating Aboriginal people about disabilities.

"Aboriginal people don't even have a word for disability", he said.

As if he is not busy enough, Paul also paints and is involved in an exhibition at the State Library, showing works by Aboriginal artists with disabilities.

"I moved up here to slow down", he said wryly.

Read original article [here](#).



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

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SEASONS
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SYDNEY**

**SAVE
THE
DATE**

Dancing In My Dreams

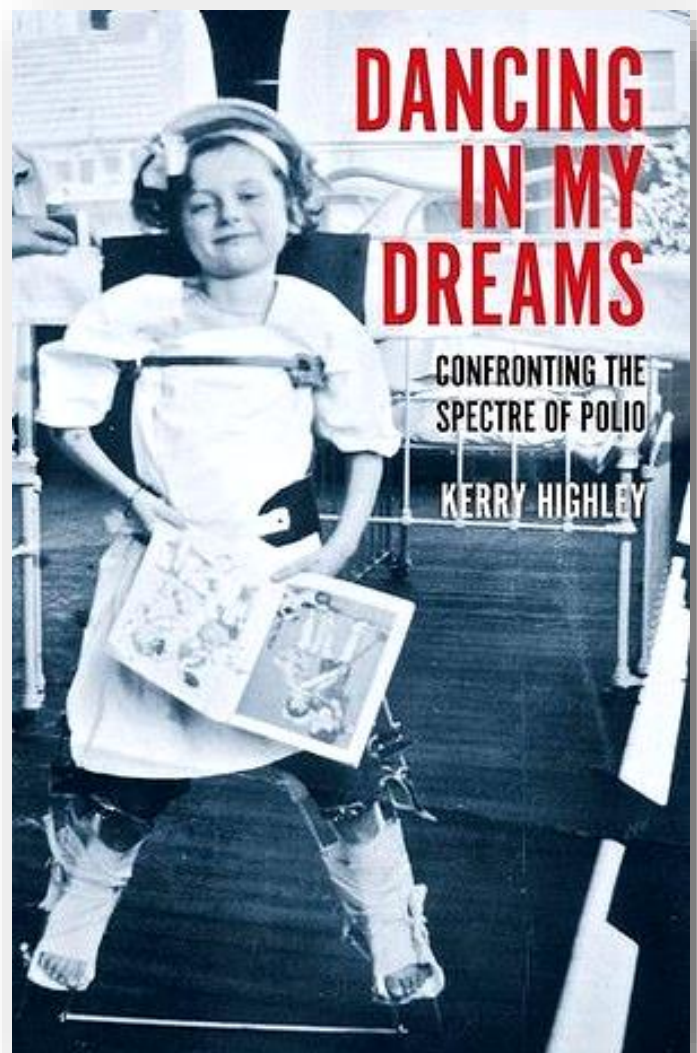
Author Dr Kerry Highley describes the background to writing her book, out now from Monash University Publishing.

Right from the start of my PhD I knew I wanted to write my thesis in the field of the History of Medicine. I had spent most of my previous working life working as a haematologist in various hospitals and pathology practices and had amassed a considerable understanding of the functions of the body at the micro level. I wanted to use that knowledge.

Pretty soon after starting my research I realised that I wanted to focus heavily on the experience of the polio survivor. I wanted to be able to tell the general public what it felt like to have survived an encounter with that tiny poliovirus—the pain, the isolation, the fear, the effort needed to find the courage just to keep trying to breathe on one's own or to practise the exercises.

Along with the survivor stories, another major theme in the book was becoming obvious to me: the major disagreement on polio treatment between Dr Jean Macnamara, the orthopaedic specialist in Melbourne and Sister Elizabeth Kenny, the self-taught nurse from outback Queensland. Their contributions to the treatment of paralysed limbs were as dissimilar as they were controversial, their stories so fascinating that, at times, they threatened to take over the entire book. Both women were big-hearted workaholics, generous with their time and unstinting in their efforts to improve the quality of life for the survivor.

Cont'd p14



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Dancing In My Dreams (cont'd from p13)

My hypothesis is that one of them was quite wrong in her approach to treatment but you will have to make up your own minds about that. I have tried to be fair to both women.

The elimination of polio is one of the great scientific stories of the twentieth century. It was a disease of the West and, paradoxically, a disease of cleanliness. Because polio has been eliminated in the West, many in the population have become complacent about immunisation, as evidenced by an increasing number of parents who choose not to have their children vaccinated against polio and other infectious diseases. Preventing an outbreak of epidemic polio in this country relies on maintaining a high level of immunity to polio within the population, preferably above 90%. If that level drops, and it is very low in some parts of northern NSW, then there is an accumulation of susceptible individuals in the population and the threat of a polio epidemic rises.

Being vaccinated against polio is like wearing a seatbelt. It can prevent you from having a serious injury but it will not prevent all injury. What it will do is reduce the severity and probably save your life. Saying you won't vaccinate yourself or your children because you could still catch the disease is as stupid as saying you won't wear a seatbelt because you could still get injured.

I hope you enjoy reading the book. 🌟

What others are saying about *Dancing in My Dreams*:

Monica Saville, Past District Governor of Rotary, launched the book at the National Library in Canberra and said: *'This book covers the effects of polio not only on the patient but on families and the community [...] Most poignantly, she has described and quoted the experiences of patients. I commend your book to a wide audience—medical people, polio survivors, the families who have been touched by polio and the general public.'*

Kristina Olsen reviewed the book for the *Sydney Morning Herald*, saying *'This wide-ranging investigation is a timely reminder that polio once was, and in some areas still is, the most feared of childhood diseases. [...] Kerry Highley draws on moving and graphic memories of polio survivors and examines the social and political context of the development of vaccines and treatments. She revisits the controversies and rivalries that raged around the 'paralysed body' and paints an often unflattering portrait of the main players, revealing the vested interests and bigotry that kept Australia behind the rest of the world in the effective care of sufferers.'* 🌟

Polio Oz News readers can receive a 20% discount off the RRP on their purchase of a copy of *Dancing in My Dreams* by entering the discount code **S-20%_POLIO** on check-out at the Monash UP website www.publishing.monash.edu.au/books/dmd-9781922235848.html

Turnbull Commits to Polio Eradication

Source: news.com
- 29 November 2015

Prime Minister Malcolm Turnbull has joined other Commonwealth leaders and UN chief Ban Ki-Moon in committing to the eradication of polio.

At the Commonwealth leaders' meeting in Malta on Saturday Mr Turnbull said he was disappointed the crippling disease had not yet been wiped out but Australia remained committed to doing that.

He said Australia was putting in another \$72 million to the eradication effort - \$36 million to the Global Polio Eradication Initiative and another \$36 million to the World Bank to support vaccination programs in

countries where polio had been eradicated to ensure it did not return.

"We are very committed to this campaign and this initiative. It's of vital importance to the people of every country", he said.

The GPEI was formed in 1988 to eradicate polio at a time when around 350,000 cases of polio were crippling and killing children in 125 countries every year.

Since then hundreds of millions of children have received polio vaccines and an estimated 13 million people have been saved from lifelong paralysis.

This year only Pakistan and Afghanistan have had cases of

wild poliovirus while all African countries have now gone a year without a single case.

Pakistan Prime Minister Nawaz Sharif said in Malta on Saturday that the number of polio cases in his country had been significantly reduced and the aim was to vaccinate every child and eliminate polio altogether.

It's estimated that it will cost an additional \$US1.5 billion to end polio and ensure hundreds of millions of children are vaccinated multiple times against the disease.

"Polio struck down many of my generation and now we are on the verge of striking down polio", said UN chief Ban.

Read original article [here](#). 🌟

Co-operation to Assist Polio Survivors

PRESS RELEASE BY EPU/RAG
7 October 2015

Poliomyelitis is a disease that is on the edge of eradication in the world thanks to the combined efforts of Rotary International, the World Health Organization, UNICEF, Centers for Disease Control (CDC) and the Bill and Melinda Gates Foundation (and other generous funders), together with the thousands of volunteers and health workers who have carried out the worldwide vaccination program.

Once the disease is eradicated there will still be in excess of 15 million polio Survivors worldwide who are going to need care, support and treatment for decades to come. Without, they are destined on the large part to shortened life expectancy, poverty and destitution certainly in the sub-Saharan Africa, the Indian sub-continent and surrounding countries.

That is why today the Polio Survivors Rotarian Action Group (RAG) and the European Polio Union (EPU) are announcing that they are pooling information and body of knowledge resources for the benefit of polio survivors and those with Post-polio Syndrome (PPS) around the world.

John R. McFarlane, President of the EPU, said *"We all acknowledge the tremendous work that has been carried by out by Rotary and its partners in bringing this virus to near extinction, and we know the final inch will be difficult but we also have to look to the future and care for all those who were unable to benefit from the vaccine for whatever reason. They need help so that they can live their lives with dignity and independence."*

Ann Lee Hussey, Chair of the Polio Survivors RAG, stated *"The eradication of this virus is the first part of a journey for those already affected that will last for the rest of their lives. There is much more to be done beyond eradication. We*

see co-operation with the EPU as the first stage in bringing the humanitarian needs of polio survivors and those with PPS to the fore, wherever they are in the world."

Polio Survivors & Associates is a Rotarian Action Group dedicated to the humanitarian assistance of polio survivors.

The European Polio Union is a group of polio survivors' support groups (21 organizations in 18 countries). It also arranges events to help and inform medical personnel and those affected by polio and Post-polio Syndrome on best practice and treatment of the condition.

The two groups have a common goal - to help and improve the lives of polio survivors and those with PPS. 🌐

EDITOR'S NOTE: On Day Three of the 2016 Australasia-Pacific Post-Polio Conference in Sydney next September, John McFarlane will be representing the EPU, joined by Polio Australia and Post-Polio Health International representatives, in interactive discussions to explore circumstances and conditions around the world which could be addressed by a strong and unified approach by regional polio peak bodies for the benefit of all polio survivors.

Other presentations will include a panel discussion to explore partnership opportunities between post-polio service providers, Rotary International, philanthropists, and government bodies to support programs for survivors of polio in both developed and developing nations.

Check the 2016 Conference Program [here](#). 🌐


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COTA NSW has pleasure in inviting you to the Australian Universal Design Conference to be held at the Sydney Town Hall on 30 – 31st August 2016.

Anyone with experience and knowledge to share about universal design, inclusive design, and liveability, is invited to submit a 300 word outline of their presentation.

The overall theme will be *Universal Design: From the Margins to the Mainstream*.

[Click here](#) to read more.

Post-Polio Syndrome: It Takes A Team Approach

By Larry Hand, freelance writer, Massachusetts

Source: LER Magazine—October 2015



A polio survivor works with Beth Grill, PT, (left) and Nick Nappi-Kaehler, PT, (back) at the International Rehabilitation Center for Polio (IRCP) in Framingham, MA (Photo courtesy of the IRCP)

Along with technical issues related to muscle weakness, fatigue, and pain, the challenges of managing this heterogeneous population include patients' emotional response to the idea of needing an orthotic

device for a disability they thought they had overcome.

There are two things practitioners can agree on regarding patients with post-polio syndrome (PPS): It takes a team approach to manage these patients effectively, and each patient is truly an individual case, unlike the last and unlike the next.

"Manage" is the key word here, because no effective pharmaceutical treatment or preventive measure exists for PPS, which, according to the National Institute of Neurological Disorders and Stroke, affects 25% to 40% of polio survivors. Recent research is sparse, compared with many other disorders, so practitioners are relying largely on longstanding studies done during the 1980s and 1990s.

A key factor in managing these patients, practitioners say, is balancing any exercise or device intervention aimed at maintaining muscle strength against the risk of possibly further weakening the same muscles. Another factor is managing what many describe as a unique patient population and their muscle weakness, fatigue, and pain.

Individual variability and lack of predictive factors underscore the need for tailored care based on actual functional decline in patients with post-polio syndrome.

"The needs of a post-polio patient can be very diverse, as can be their willingness to accept intervention," said Phil M. Stevens, MEd, CPO, of the Hanger Clinic in Salt Lake City. "The challenge with post-polio is that there is a lot of emotional history tied up in the individual. Most of them had to wear some type of orthopedic brace in an era when any sort of disability was poorly accepted by humanity. Many of these patients have since worked very hard to overcome and compensate for those muscle weaknesses and many of them reached a level where they can do so without braces."

However, Stevens noted, as that generation of polio patients continues to age, those compensatory mechanisms tend to have a cumulative effect.

"Many patients feel like they've overcome the disability of their youth and now they're being forced to confront it again," he said. "I have had many patients with post-polio who broke down in the treatment room because of the emotional component of getting a brace for a disability they thought they had already overcome."

Among the recently published research papers is one from the Netherlands that illustrates the individuality of PPS patients. Researchers followed 48 PPS patients over 10 years to assess their rate of decline in walking capacity and physical mobility. They found that average walking capacity declined 6% and mobility declined 14% as the patients also lost an average of 15% of isometric quadriceps strength.

However, almost one fifth of the patients lost substantial walking capacity (27%) and mobility (38%), and loss of quadriceps strength accounted for only 11% of the walking capacity decline. Baseline values did not predict decline, either.

"The individual variability, yet lack of predictive factors, underscores the need for personally tailored care based on actual functional decline in patients with post-polio syndrome," the researchers wrote.

The same group of researchers conducted another study that found ultrasound monitoring can be helpful in assessing patients' disease severity and changes.

Another Dutch study found that usual care trumped both exercise therapy and cognitive behavioral therapy in treating 68 PPS patients but found no explanations as to why.

Swedish research on late effects of polio, which is closely related to PPS but had a different diagnostic code until the implementation of ICD-10 this year, has revealed risk factor variability similar to that reported in the Netherlands.

A study published in the March 2015 issue of *PM&R* found that knee muscle strength explained only 16% of the variance in the number of steps per day taken by 77 patients with late effects of polio, and gait performance only explained between 15% and 31% of the variance. A second study from the same group, published in the July 2015 issue of the *Journal of Aging and Physical Activity*, found that self-reported outcome measures of physical activity were only weakly to moderately correlated with self-reported disability.

PPS patients are often highly motivated, said Beth Grill, PT, of the International Rehabilitation Center for Polio (IRCP), in Framingham, MA. But that can also end up working against them.

"Polio survivors are very independent, motivated individuals and are often described as Type A personalities. They have overcome so much in their lifetime that when they develop post-polio and they are no longer able to do the things that they have always done, it can be devastating," Grill said.

Read full article [here](#).

Minister's Speech Signals a Revival of Health Reform

By Vern Hughes

Source: [National Campaign for Consumer-Centred Health Care email update](#)

On Wednesday the Federal Health Minister Sussan Ley delivered a terrific address to the National Press Club on health reform. [Click [here](#) for PDF.]

The speech is very hopeful and signals a revival of health reform following the change of Prime Minister last month. Under Minister Peter Dutton, there were no signs of interest in health reform. But Sussan Ley's speech is about placing the consumer at the centre of the health system, finding alternatives to fee-for-service in chronic and mental illness, re-instating a person-controlled electronic health record with an opt-out rather than opt-in process, and emphasising innovation in preventing illness and over-servicing.

These themes are very much in accord with our agenda for consumer-centred health care. We can now reactivate our campaign, taking up our agenda with the knowledge that the Commonwealth is interested in moving forward.

Below, I have summarized the key points in Sussan Ley's address. Note the changes in terminology (Medicare Locals are now rebranded as Primary Health Networks; and the Person-Controlled Electronic Health Record will now be known as My Health Record).

The four key points in Sussan Ley's Address are:

1. Chronic illness and mental health require alternatives to fee-for-service, which is only



- suited to acute and episodic care. A *Primary Health Care Advisory Group* has been appointed to review new and existing funding models in these areas, with a brief to propose new funding models to 'deliver more localized and more personalized care'. This Group is headed up by Dr Steve Hambleton;
2. A *Mental Health Expert Reference Group* is providing advice to Government on how best to implement the broad ranging recommendations of the *National Mental Health Commission's* Review and take them from paper to policy, headed up by Kate Carnell;
3. A community consultation on private health insurance, to remove unnecessary regulations and allow more innovation from insurers, headed by Graeme Samuel;
4. Two trials of *My Health Record*, on an opt-out basis, involving 1 million consumers in Far North Queensland and the NSW Nepean Blue Mountains region.

The 31 Primary Health Networks, operational since July, replace the 61 Medicare Locals. Alternatives to fee-for-service in chronic and mental illness will be developed and trialed in these regions, so we have an opportunity now to take a lead role in organizing consumers and carers in these regions to prepare and put forward new funding models based on purchasing integrated and holistic health care to keep pools of consumers in these regions healthy and well.🌈

Australia to Allow Marijuana Trials

Australia to Allow Marijuana to Be Grown Locally for Medical Trials

By Morag MacKinnon

Source: Reuters Health Information
– 20 October 2015

Australia is altering its drug laws to allow for the cultivation of marijuana for medicinal and scientific purposes, removing a major hurdle to the establishment of clinical trials of the drug, the government said on Saturday.

Draft amendments to the Narcotics Drugs Act are being finalised to allow for the controlled cultivation of marijuana, giving patients access to "a safe, legal and sustainable supply of locally produced products for the first time", Health

Minister Sussan Ley said in a statement.

Australian manufacturers, researchers and patients currently have to access international supplies of legal medicinal marijuana, with cost, limited supply and export barriers making this challenging.

Allowing for the controlled cultivation of marijuana in Australia will provide the critical "missing piece" where laws already exist to licence the manufacture and supply of medicinal cannabis-based products, but local production of the crop remains forbidden, Ley said.

"This government is incredibly sympathetic to the suffering of those Australians with debilitating illnesses and we want to enable access to the most effective medical treatments available", Ley said.

Australia to Allow Marijuana Trials *(cont'd from p17)*

The government plans to create a licensing scheme to ensure that the cultivation of marijuana meets Australia's international obligations and to manage the supply of the drug from farm to pharmacy.

"Allowing the cultivation of legal medicinal cannabis crops in Australia under strict controls strikes the right balance between patient access, community protection and our international obligations."

Several Australian states have already announced clinical trials for medicinal cannabis.

Under Australian law, decriminalisation and medical trials come under state government jurisdiction. The Federal government is responsible for the regulation of the growing and importation of the drug.

The proposed changes to the legislation could pave the way for a new medicinal cannabis industry with export potential.

Last year, Australia's first initial public offering in a medicinal marijuana company, MMJ PhytoTech Ltd, was three times oversubscribed. 🌿

Nerve Pain Fact Sheet

Source: Painaustralia eNews Issue 58 - December 2015



Nerve Pain Fact Sheet Now Available Painaustralia has partnered with Healthshare and Pfizer, to produce a fact sheet aimed at helping consumers better understand neuropathic pain.

Neuropathic pain, or nerve pain, is commonly reported as the most severe form of pain. Some of our real stories reveal just how challenging it can be.

However, it can be very difficult to identify, and diagnosis of more complex cases may take some time.

Nerve pain can be present in an area with no feeling, and it can cover an unusual area. It can be present due to an underlying condition, or in conjunction with pain from other causes, or unrelated to any obvious cause.

It can feel like shooting, radiating, tingling, crawling, stabbing or burning; a sensation of heat or coldness; the feeling of pins and needles or electric shocks; or even

numbness. There can also be pain from external stimuli not normally painful.

Without treatment, it can lead to devastating impacts on a person's life, and it is important people with chronic nerve pain learn more about it. Please download the fact sheet from the [Painaustralia Patient Resources](#) page or [Healthshare](#). 🌿

Inflammation and Depression

Inflammation Fans Flames of Depressive Symptoms

By Megan Brooks

Source: [Medscape Medical News](#) / [Psychiatry](#)
– 20 November 2015

A new study supports a link between inflammation and depression and adds to the literature by associating inflammation with specific symptoms of depression, including sleep troubles and lack of energy and appetite.

Individuals with depression are known to have elevated levels of inflammatory markers, such as

C-reactive protein (CRP), and it has recently been suggested that this association may be symptom specific, Markus Jokela, PhD, from the University of Helsinki, Finland, and colleagues note in a research letter [published online](#) November 18 in *JAMA Psychiatry*.

"Higher levels of inflammation are particularly likely to underlie depression symptoms that characterize sickness behavior, including fatigue, reduced appetite, withdrawal, and inhibited motivation. From an evolutionary perspective, such symptoms have the beneficial effect of preserving energy resources for use in fighting infection and promoting healing processes", they say.

Cont'd p19

Inflammation and Depression (*cont'd from p18*)

Dr Jokela and colleagues tested the hypothesis that the association between CRP and depression is symptom-specific using data on roughly 15,000 men and women who participated in three US National Health and Nutrition Surveys. The mean age of the participants was 47.5 years, and the median CRP level was 2 mg/L (interquartile range, 0.8 - 4.7 mg/L).

"Inflammation was associated with a range of depression symptoms, particularly with tiredness, lack of energy, sleep problems, and changes in appetite", the investigators report. These symptoms characterize sickness behaviors seen in people who are physically ill.

Inflammation was also associated with cognitive and emotional symptoms of depression, including anhedonia, depressed mood, feelings of self-worth, concentration, and suicidal ideation, although these associations were not independent of the other depression symptoms. *"Further research is needed to determine whether changes in inflammation predict changes in specific symptoms and to identify metabolic pathways that mediate such changes", Dr Jokela and colleagues conclude.*

Role for Anti-inflammatory Agents?

Reached for comment, Golam Khandaker, MBBS, MPhil, MRCPsych, PhD, clinical lecturer, Department of Psychiatry, University of Cambridge, United Kingdom, told *Medscape Medical News* that *"while the association between inflammatory markers such as CRP and depression is well known, studies such as this looking at particular symptoms provide important clues for mechanism of illness pathogenesis.*

"This work points to a potentially important role

for inflammation in the pathogenesis of the so-called somatic symptoms of depression, such as sleep problems, anergia, and loss of appetite, which are, of course, an integral part of the syndrome of depression", Dr Khandaker said.

The findings, he added, *"may help to identify patients who would benefit from immunotherapy. It may be tempting to speculate from the results that anti-inflammatory drugs would be helpful for patients with predominantly somatic rather than psychological symptoms of depression. However, there is a need to carry out RCTs [randomized controlled trials] of anti-inflammatory drugs in depression to test this assumption."*

As previously reported by *Medscape Medical News*, a recent meta-analysis of 14 relevant randomized, placebo-controlled studies found that nonsteroidal anti-inflammatory drugs (NSAIDs) may help ease depressive symptoms.

Results showed that the adjunctive use of NSAIDs was associated with improved antidepressant treatment response without an increased risk for adverse effects. In particular, add-on treatment with celecoxib (*Celebrex*, Pfizer Inc) improved antidepressant effects, remission, and response.

The study had no commercial funding. The authors report no relevant financial relationships. JAMA Psychiatry. Published online November 18, 2015. [Abstract](#)



Soccer On A Scooter

He sometimes crawled to school, he plays soccer on a scooter

Source: wbez.org—3 November 2015

Polio paralyzed Sani Muntari as a child. That didn't keep him from school or off the soccer field. And he's played a key role in making Nigeria polio-free.

When Sani Muntari was 2 years old, he loved to run around and play games with his older siblings and cousins.

They lived in Sokoto, a hot, dusty city in northern Nigeria known for its deep Islamic roots. Sometimes, Muntari would go with his mother to the central market where she worked as a trader, peddling everything from vegetables to t-shirts to soap.

Then one night, Muntari came down with a fever. A few days later, his parents noticed he was having trouble walking. Soon, he couldn't move his legs. By the time he saw a doctor, he was paralyzed from the waist down. He was diagnosed with paralytic polio. He was the only person in his extended family of 37 to be affected.

During the next few years, Muntari's leg muscles atrophied and his legs became unnaturally bent beneath his body — a common progression of the disease. He continued to play with his siblings and cousins, but from a seated position. The only way he could get around was to crawl — swinging his lower body between planted hands — or be carried.

Soccer On A Scooter (cont'd from p19)



Polio survivors compete in a para-soccer tournament in Abuja, Nigeria

Then, when he was 6 years old, Muntari's parents posed a difficult question. *"They asked me if I wanted to go to school"*, Muntari says. They were concerned about how he would be treated by students and teachers. Plus, the school had no disability services. Perhaps, his mother suggested, it would be better to just stay at home. *"She told me, 'I don't want you to suffer'"*, he says.

But Muntari insisted on going. So his parents took turns carrying him the roughly one-mile distance to school. When they couldn't go, he would crawl along the busy sidewalk, past street vendors and mosques, as motorcycles and taxis whizzed by. When he got a little older, his father — a civil servant — bought him a hand-powered

tricycle. *"My father really encouraged me to stay in formal education, to become a useful member of society. I'm really happy for that"*, he says.

Soccer On A Scooter

In honor of World Polio Day on Oct. 24, Rotary International invited para-soccer teams from around Nigeria to participate in a tournament in the capital, Abuja. Nigeria's para-soccer league was formed to provide polio survivors with the benefits of a competitive sport — better health, more confidence and a physical and emotional outlet.

To play, Muntari sits on a small wooden scooter — a twelve-inch wooden square with four swiveling wheels — which is how many polio survivors in Nigeria get around. Scooter users propel themselves forward by pushing their hands on the ground.

Dr Tunji Funsho, the head of Rotary International's polio efforts in Nigeria, says he's seen these teams play for years, but is always amazed by their athleticism. *"The agility and the skill displayed is incredible"*, he says. Funsho hopes the league will play a part in changing people's attitudes about polio survivors. *"We know for another half century at least, we are going to have people that have to live with the consequences of polio"*, he says. 🌈

Polio Yogi Making Country Proud

By Basant Kumar

Source: www.iamin.in - 3 December 2015

Having achieved the feat of becoming an international yoga demonstrator at a very young age, a 21-year-old JNU student affected with polio recently made the country proud by setting a record for 'Most Flexible Handicapped Yoga Champion' 2015 in Unique World Records, a world record book of Indian origin.

Tejaswi Sharma, who is 69 per cent physically disabled, can perform the hardest of the asanas. He has been practising yoga since the age of 5.

Tejaswi, a student of German language, has also won several international and national championships in yoga. He has won silver in the World Cup Yoga championship held at Talkatora stadium in 2011 and a gold medal in a Yoga championship held in Hong Kong in the year 2012. Besides he also won the second position in the fourth International Yoga championship held in Shanghai last year.

"I have been practising Yoga since childhood. This is the reason why I have a flexible body. I studied in Noida's Maharishi Vidya Mandir where my teachers never encouraged me to participate in games. However, in the year 2009 I participated in an inter-school yoga championship and fared well". He further adds, *"During school days, I used to show yoga asanas to my friends, who were always supportive of my act"*. Tejaswi has been encouraging specially abled people to do what they aspire to do and ignore what people have to say.

This is a translated copy. Read the full story [here](#). 🌈



Toward Elimination of Poliovirus In The Lab

By Rina Shaikh-Lesko

Source: www.the-scientist.com
—16 November 2015

As the world inches closer to polio eradication, laboratories studying the virus will have to bolster biosafety standards. Eventually, most will need to stop working with the pathogen entirely.

In September, the Global Polio Eradication Initiative (GPEI) [declared](#) type 2 poliovirus eradicated. This long-awaited statement officially confirmed what polio researchers and global public health officials had known for more than a decade: one of the triumvirate of polioviruses was no longer a threat. The [last case of type 2 poliovirus](#) was diagnosed in Northern India in 1999.

The announcement also set in motion a critical component of the GPEI's Poliovirus Eradication Endgame Strategic Plan. Among other things, public health officials are planning to stop using oral polio vaccine against type 2 poliovirus in April 2016. To reduce risk of accidental release, all laboratories that stock type 2 poliovirus—both the wild-type and vaccine virus—will need to destroy the virus soon after that date, or adopt stricter standards for handling it.

Containment of type 2 poliovirus, *"really is a step forward to containment of type 1 and 3"*, said [Walter Dowdle](#), a consultant to the Task Force for Global Health and former deputy director of the US Centers for Disease Control and Prevention (CDC).

This transition for handling laboratory stocks of type 2 poliovirus will likely be a dress rehearsal for eradication of all types of poliovirus—something that may occur before the decade is out. One cost of this progress, though, will likely be halting nearly all basic research into poliovirus as most academic researchers are unlikely to have the funding to upgrade their containment facilities.

Currently, there are about 500 laboratories working with type 2 poliovirus worldwide. After the new requirements go into effect, there will be around 50 facilities — including both laboratories and vaccine manufacturers — according to [Nicoletta Previsani](#), polio containment coordinator at the World Health Organization (WHO). This reduction of stored samples will require a huge coordinated effort on the part of laboratories and other facilities holding type 2 poliovirus, as well as on the parts of national certification boards charged with ensuring the virus is properly handled by any remaining facilities in each country.

"There are two steps to containment", said Previsani. First, "reducing the number of those facilities [handling type 2 poliovirus]". The second, she added, is ensuring that "poliovirus essential facilities — who are tasked with maintaining stocks of virus — really implement those [containment] measures."

Worldwide, the number of cases of polio infection dropped dramatically after vaccines were developed in the 1950s. In 1988, a decade after the last smallpox case, the WHO unveiled its plan to eradicate polio. The effort, steered by the GPEI, has hit roadblocks in the past, but now appears [poised to reach its target](#) of eradication by 2018. Polio now only circulates in Afghanistan and Pakistan. (Nigeria was officially [declared polio-free earlier this year](#).) Health officials haven't seen type 3 cases since 2012, but it will take a few years to verify that this pathogen is no longer circulating.

This year, there have only been 52 reported cases of polio—a record low. Meantime, health officials called for the removal of type 2 poliovirus from the [oral vaccine](#). Within months of this switch, only laboratories doing crucial poliovirus work will be allowed to maintain stocks of type 2 poliovirus. All others will need to destroy their samples. Essential facilities will also need to meet strict requirements. In the U.S., this will mean poliovirus will move from a biosafety level 2 (BSL2) — a designation meant for mild or hard-to-contract diseases — to BSL 3 — meant for serious or potentially lethal diseases.

The WHO has developed a 16-point biosafety management [plan](#) for labs that will continue to handle the virus. Its strategy calls for containment facilities to be limited to regions where polio vaccination levels are high, to prevent human infections in case the virus is accidentally released. Containment facilities also need to be in areas with sewage systems that are not open to the environment and have the capacity to properly treat effluent, according to the WHO.

Even among countries that meet all these requirements, few are ready to make those changes quickly and have the regulatory infrastructure in place to certify that labs and facilities are following guidelines, said Previsani. *"In general, everyone's late. The discussions are really only just starting, so containment will be addressed in terms of interim measures for next year."*

Another challenge will be overseeing labs that store polio-contaminated specimens, such as frozen stool samples collected to study cholera or rotavirus.

Elimination of Poliovirus In The Lab *(cont'd from p21)*

"They may not realize the samples are contaminated, so the effort needs to reach out to these people", said Previsani. "Those poliovirus contaminations may not mean much in terms of the eradication program, but they may be asked to destroy them [the samples] or contain them."

One consequence of eliminating nearly all type 2 poliovirus is that it will slow research down.

"There's a tension between stopping work [on poliovirus] and doing enough work to make sure eradication continues", said Philip Minor, head of virology at the National Institute for Biological Standards and Control in the U.K., who was part of the team that drafted the current polio eradication plan. "You do need to strike the right balance . . . making sure you don't stop work that really matters for the endgame."

Take, for example, work being done in [Raul Andino's](#) lab. Andino, a virologist at the University of California, San Francisco, and his colleagues are developing a new oral polio vaccine. But the new containment requirements could mean the team won't be able to progress its candidate to clinical trials. If polio is eradicated on schedule, this candidate vaccine would essentially serve as an emergency backup. But if GPEI misses its target, a novel vaccine may be a useful tool in the next stages of eradication. *"The question is, do you need to work with type 2 in order to develop new vaccines, new drugs, new diagnostic tools?"* he said. *"It's really a cat-and-mouse type of race: Do you do more research or . . . close your eyes and hope for the best?"*

"It's a very wise idea to document who has this virus. It's something that has to be done", Andino continued. But more-stringent biosafety

regulations could mean the end of poliovirus research in academic labs. *"I can tell you that it will kill the field",* he said.

"There's a growing sense in the picornavirus community that all research on poliovirus should not stop. We should maintain some research", said [Kurt Gustin](#), a virologist at the University of Arizona College of Medicine in Phoenix who studies host-pathogen interactions. *"One virus isn't equal to another virus",* he said. *"They take advantage to other machinery and all do it in interesting and unique ways. Simply studying other viruses won't tell us how poliovirus and closely related viruses do their job."*

Gustin's group is currently working only with poliovirus types 1 and 3, so the team won't be affected by the impending regulations. But the virologist is thinking ahead to when other types of poliovirus are eradicated. *"Based on the surveillance we're seeing, I'm taking it a lot more seriously than I was three years ago",* said Gustin. *"It's at the forefront of thoughts more often."*

Some polio researchers may choose to work on different viruses, said [Esther Bullitt](#), a virologist at Boston University who studies proteins involved in poliovirus replication. Bullitt told *The Scientist* she, herself, has considered doing so.

"Eradication would be awesomely great", she said. *"It's absolutely something to look forward to."* Even if it means a significant shift in her own research, added Bullitt, *"the fact that poliovirus will be eradicated will be worth what it takes to make that happen."*

Read original article [here](#). 🌐

Fears of Epidemics in EU

Fears of epidemics in EU - HIV, polio, cholera and more detected in refugee camps

Source: belfasttelegraph.co.uk - 09/12/2015

The influx of asylum seekers has brought health concerns to Europe. About 15% of newly arriving migrants (approx. 200 000 people) require immediate treatment. Doctors admit some of the illnesses have been transmitted by refugees and the EU is not ready to provide its citizens with appropriate treatment. Several diseases represent a real people's life threat: cholera; HIV; Hepatitis A, B, C, E; polio; malaria; leishmaniasis; etc.

Click [here](#) or on the picture (right) to watch video.



Polio Outbreak In Europe

By [Paul Abernethy](#)

Source: Global Citizen – 9 December 2015



The World Health Organisation (WHO) has called on the Ukraine government to declare a state of emergency following a recent outbreak of polio in the country. Earlier this year the Ukraine announced two new polio cases--the first in Europe since 2010. The WHO are hoping that by declaring a state of emergency, it will prompt more action from the government in Kiev.

A perfect storm is brewing in the country that, if left unchecked, could have disastrous consequences for the Ukraine, and indeed, the world. In Ukraine only 50% of its children are vaccinated against polio -- an extremely low rate for a developed country. And with the country currently torn by fighting, vaccine programmes can struggle to reach the children that need it the most.

The oral polio vaccine, like many vaccines, contains a weakened live virus that helps your body build immunity. In extremely rare cases, this can mutate and infect people close by who have not been vaccinated against the disease. This is what happened in the Ukraine when two unvaccinated children, one just 10 months old, were paralysed by the virus.

In the majority of countries in the world, this isn't an issue as vaccine coverage rates are extremely high. But because only half of the Ukraine's children are covered by the vaccine, there are grave concerns that this could escalate if not dealt with immediately.

Action is underway though. In October the Ukrainian government, with the help of Canada, launched a polio vaccine campaign that hopes to vaccinate 90% of children under 5. It is hoped that if the government takes the advice of the WHO and declares a state of emergency, other government departments will mobilise to support the campaign.

The outbreak in the Ukraine reminds the world of the importance of vaccination programmes. Without universal coverage, cases like Ukraine could become a recurring issue, unravelling 30 years of exemplary work that has seen 99.9% of the virus eradicated.

A scary thought that needs immediate attention.

Read original article [here](#).

Read about [Ukraine's Crazy Polio Outbreak](#) by [Kent Sepkowitz](#).

Ending Polio: We're On The Verge of Making History

Dr Sue Desmond-Hellmann, Special to CNN

Source: CNN - 22 October 2015

A huge immunization drive in Nigeria has meant there have been no new cases of polio for more than a year.

Story highlights

- Africa has gone a year without a child paralyzed by wild poliovirus.
- Africa's success should energize the world's efforts to end polio forever, says Dr Sue Desmond-Hellmann.
- "We have never been closer to wiping out this terrible disease", she says.

Dr Sue Desmond-Hellmann serves as CEO of the [Bill & Melinda Gates Foundation](#). The opinions expressed in this commentary are hers.

A bucket of human waste is a thing of beauty. That might sound peculiar, but let me explain.

In June of this year, I traveled to Nigeria to see firsthand the hard work of eradicating polio. At the time, the country was on the verge of going a full year without a case of the disease. During part of my trip, I spent time learning about disease surveillance.

That is where the bucket came into play. Haliru Usman is an environmental health officer in Kaduna state whose job it is to test sewage for the polio virus. Once a week, he takes out his bucket, rubber gloves, and bleach wipes to collect a sewage sample. He then packs it on ice, which can be difficult to come by, and makes an eight hour drive to a laboratory for testing.

This is clearly a challenging and smelly global health job.

Ending Polio *(cont'd from p23)*

It is also unbelievably important. Vigilant disease surveillance is critical to the global goal of eradicating polio. Mr Usman took pride in doing his work, because he knew it would help save lives.

Thanks to his dedication — and to the commitment of the Nigerian government, the Global Polio Eradication Initiative (GPEI), and thousands of heroic health workers — Nigeria reached the milestone of a year without polio one month after my visit. For the first time in recorded history, the entire African continent has gone a full year without a child paralyzed by wild poliovirus. To officially certify Africa polio free, we must protect this progress through 2017.

That brings me to the present: World Polio Day. Africa's success should inspire and energize the world's efforts to end polio once and for all. But our reflection shouldn't stop there. This is also a reminder of the momentum we must sustain to wipe out polio in the two remaining endemic nations: Pakistan and Afghanistan.

Partners such as the United Arab Emirates have already been critical to getting the polio vaccine to thousands of previously unreachable children in the region — but there is more to do.

Nigeria's fight against polio

It will take lots of buckets. It will take health workers going door to door with vaccines. Above all, it will take the continued commitment of developing countries, wealthy nation governments, and individual donors to ensure we wipe out one of humanity's oldest scourges.

We are on the verge of making history, and everyone has the opportunity to contribute.

Today is the start of a [48-hour World Polio Day Donation Challenge](#). The Gates Foundation will triple your impact by matching your donation to Rotary International 2-to-1.


In the fight against polio, a little goes a long way. The oral polio vaccine, for example, costs as little as 14 cents a dose.

I am inspired by the progress the world has made to eradicate polio. Since the launch of the [GPEI](#) in 1988, polio cases have dropped by more than 99% worldwide—from more than 350,000 a year to fewer than 100 so far in 2015.

We have never been closer to wiping out this terrible disease, and we cannot stop short. As long as polio exists anywhere, we risk its resurgence—especially among the poorest and most vulnerable people.

Now is the time to make certain that no child will be paralyzed from polio ever again.

Wouldn't that be a thing of beauty, too?

Read original article [here](#). 



Polio This Week

Source: [Polio Global Eradication Initiative](#) — as of Wednesday 9 December 2015

Wild Poliovirus Type 1 and Circulating Vaccine-Derived Poliovirus Cases

Total cases	Year-to-date 2015		Year-to-date 2014		Total in 2014	
	WPV	cVDPV	WPV	cVDPV	WPV	cVDPV
Globally	66	23	324	48	359	56
- in endemic countries	66	2	305	45	340	52
- in non-endemic countries	0	21	19	3	19	4

Case Breakdown by Country

Countries	Year-to-date 2015		Year-to-date 2014		Total in 2014		Onset of paralysis of most recent case	
	WPV	cVDPV	WPV	cVDPV	WPV	cVDPV	WPV	cVDPV
Afghanistan	17	0	24	0	28	0	03-Nov-15	NA
Pakistan	49	2	275	20	306	22	21-Nov-15	09-Feb-15
Cameroon	0	0	5	0	5	0	09-Jul-14	NA
Equatorial Guinea	0	0	5	0	5	0	03-May-14	NA
Ethiopia	0	0	1	0	1	0	05-Jan-14	NA
Guinea	0	1	0	1	0	1	NA	20-Jul-15
Iraq	0	0	2	0	2	0	07-Apr-14	NA
Lao PDR	0	5	0	0	0	0	NA	28-Oct-15
Madagascar	0	10	0	1	0	1	NA	22-Aug-15
Myanmar	0	2	0	0	0	0	NA	05-Oct-15
Nigeria	0	1	6	24	6	30	24-Jul-14	16-May-15
Somalia	0	0	5	0	5	0	11-Aug-14	NA
South Sudan	0	0	0	2	0	2	NA	12-Sep-14
Syrian Arab Republic	0	0	1	0	1	0	21-Jan-14	NA
Ukraine	0	2	0	0	0	0	NA	07-Jul-15

[Circulating vaccine-derived poliovirus](#) cVDPV: Madagascar is cVDPV1, all others cVDPV2. NA: onset of paralysis in most recent case is prior to 2014. cVDPV is associated with ≥ 2 AFP cases or non-household contacts. VDPV2 cases with ≥ 6 (≥ 10 for type1) nucleotides difference from Sabin in VP1 are reported here. 🌐