



Volume 6, Issue

Polio Oz News

June 2016 – Winter Edition

A Taste Of Things To Come

The following [abstract](#) is one of the presentations which make up the Program for the Australasia-Pacific Post-Polio Conference – *Polio: Life Stage Matters* from 20-22 September in Sydney. Check the website for all details: www.postpolioconference.org.au.

Management of Spinal Issues in Polio Patients

By Carol Vandenakker-Albanese, MD

University of California, Davis, Health System

The spine provides structural support of the trunk and stabilizes the limbs. The polio virus attacks the motor nerves in the spinal cord, resulting in varying degrees of paralysis of muscles. This causes asymmetry of skeletal support and bone, altering posture and function.

These changes result in: loss of bone strength, altered body mechanics, secondary deformity, increased stress on spine segments and increased stress on supporting soft tissues. Related spinal problems in the polio survivor include: spinal deformity, osteoporosis, accelerated degeneration, and nerve impingement secondary to spine degeneration that can mimic post-polio syndrome.

The risk of scoliosis in a polio survivor is 30%. Progression of the curve is correlated to degree of weakness and age at onset. Bracing is often unsuccessful in preventing progression and surgical fusion is often recommended. Progression of scoliosis can continue after skeletal maturity due to degenerative changes. Progression can cause an unbalanced spine, bony pressure points, and/or reduced lung function.

Polio survivors are at increased risk of osteoporosis based on: reduced peak mass, reduced muscle action on bone, and reduced mobility. Spine (vertebral) fractures may occur with trauma or spontaneously.

Spine degeneration is common in polio patients. Stress on the spine is increased by asymmetry of muscle support, postural changes and altered mechanics of movement. Degeneration can



include slippage of vertebrae, enlargement of joints and ligaments and bulging discs. Degenerative changes may result in compression of nerves. Single level nerve compression can cause pain, weakness and/or loss of sensation in a limb.

Spinal stenosis refers to narrowing of the spinal canal, often as a result of degenerative changes. Symptoms can include: loss of balance and aching in the legs that increases with standing or walking. Pain is usually relieved with sitting or walking with shopping cart or walker and may be confused with symptoms of post-polio syndrome.

Medical evaluation is important to diagnose and focus treatment. Treatment options for spine conditions include: postural adjustments, activity modification, physical therapy, medications for pain control, bracing, injection procedures, and surgical intervention. Spine bracing is safe but not always tolerated. Braces reduce motion and provide support. Spinal injection procedures may be very helpful for inflamed nerves or joints. Nerve blocks can help alleviate pain from joint degeneration, but relief is usually temporary. Surgery may be considered when pain or nerve compression results in loss of function. Spine surgery is often major surgery with significant risks.

The preferred management of spinal conditions in a polio patient is conservative. Treatment should focus on changes in lifestyle, activity modification and a therapy program that includes postural correction, strengthening, stretching and cardiovascular conditioning. ●



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From the President

*Dr John Tierney OAM
President*

A few weeks ago Polio Australia Board member Sue Mackenzie, who is our (pro bono) fundraiser extraordinaire, put on in Brisbane her second successful event, a *Rio Carnivale Party*.

This event raised just under \$8,000 dollars in urgently needed funds to support the work of Polio Australia. On page six there is a full report of this highly entertaining event, which my wife Pam and I, and two other family members attended. They didn't realize that polio survivors could have such fun!

A funding cloud on the Polio Australia horizon is the difficulties created for our major fund-raiser, *Walk with Me*, after the organising body, *Ability First Australia*, lost its anchor sponsor *Dick Smith* when the business collapsed a few months ago. Gillian Thomas is leading negotiations on Polio Australia's behalf to re-establish this event under a new arrangement on the Polio Australia calendar.

Usually this event is held in September, but because of the Australasia-Pacific Post-Polio Conference in Sydney in September, at this stage we are thinking that the walks might be held as close as possible to *World Polio Day* on the 24th October. After a few years of raising a lot of money from this fundraiser, last year our efforts tailed off because fewer people took part.

I would really encourage you all to think about joining *Walk with Me* in October and approaching your family, friends, work colleagues and / or people in community groups that you know well to sponsor your participation. Again Sue Mackenzie has stepped

up to assist us with our efforts to reboot this event to once again become our major fundraiser. And having personally experienced Sue's creative flair, I'm sure there will be a distinctive festive feel to whatever she does.

I was recently invited by our friends across the ditch at Polio New Zealand to take part in their annual retreat which this year will be held in Rotorua in August. Since the appointment of Gordon Jackman to work full time on Polio New Zealand programs, Polio NZ has developed a range of initiatives to further the objectives of their organisation. When I am at the Polio NZ retreat, I look forward to catching up on their plans for the future. I will also be encouraging their members to join with us at our Australasia-Pacific Post-Polio Conference.

The conference registrations are going well, so please don't miss this opportunity to take part and learn about how to better manage your post-polio condition from the outstanding panel of Australian and international experts who have agreed to take part pro bono. Our conference received a terrific boost recently from a sponsorship of \$24,000 from the NSW Department of Health. To register for the conference please click this [Register Now](#) link.

Polio Australia is highly dependent on private donations to fund its work with the post-polio community. In the Autumn edition of *Polio Oz News*, I outlined initial progress on our work in developing a more robust *bequest* program. I wish to acknowledge the terrific work that Mary-ann has put into the development of this program and her and Jill Pickering's generosity in funding a dedicated part-time position at Polio Australia to advance this fund raising initiative. When you are updating your Will, we would like you to consider supporting the work of Polio Australia with a bequest. 🍷

John

From the Editor



Mary-ann Liethof
Editor

As we hurtle through the year at break-neck speed, excitement is mounting in the lead up to the Australasia-Pacific Post-Polio Conference taking place in Sydney from September 20-22 (P8). I am in absolute awe of all the presenters who are funding themselves to be there to share their experience, skills and knowledge with the delegates. Whilst there is much

discussion about the lack of information amongst health service providers in relation to working with the post-polio body, this Conference demonstrates a clear generosity of spirit from those who *do* have the knowledge. The combination of European, American, Australian, and wider world experts coming together to present on "*Polio: Life Stage Matters*" is unprecedented and unlikely to occur again. Do not miss this major event!

The LEO Clinical Practice Workshop series has been heralded as a great success (P4), and we now have 130 Sydney-based health practitioners who know about the condition. We can only hope to generate the interest and funding to facilitate these Workshops further afield.

And we are delighted to see that things are coming together for our cousins 'across the ditch' in New Zealand (P9), with funding from the Duncan Trust to provide training opportunities for health professionals wanting to learn more about the late effects of polio. What a wonderful

boon! We are very envious of this generous funding source here in Australia!

I was quite moved by poem penned by Peter Willcocks on his battle to get going in the morning (P12). It certainly put my grumbles into perspective.

And did you know that a Sister Kenny Clinic operated in Newcastle (NSW) between 1936-1943 (P12)? Although many would regard Sister Kenny as a rather controversial figure, her methods were certainly known and practised far and wide.

Also in this edition are contributions from the 'other' NDIS (Not Damn Interested In Seniors) campaigner, Lori Grovenor (P13); and Kristy Rackham, RN, guides us through the secrets of meditating and insists you can't 'do it wrong', so why not give it a try?

June 20-26 is World Continence Week, and you will find some helpful advice on how to manage this often unspoken-about condition (P17).

As always, there are a variety of news items based on the polio vaccine, with a couple of interesting reports on the incredibly ambitious 'Switch', whereby 155 countries changed their polio vaccine regime over a 2 week period during April. (P18 and P20).

For those of you who have read previous articles on the polio virus being used to fight brain cancer, a review of a related '60 Minutes' program will provide a few salient points to consider (P22).

Please enjoy! 🌟

Mary-ann

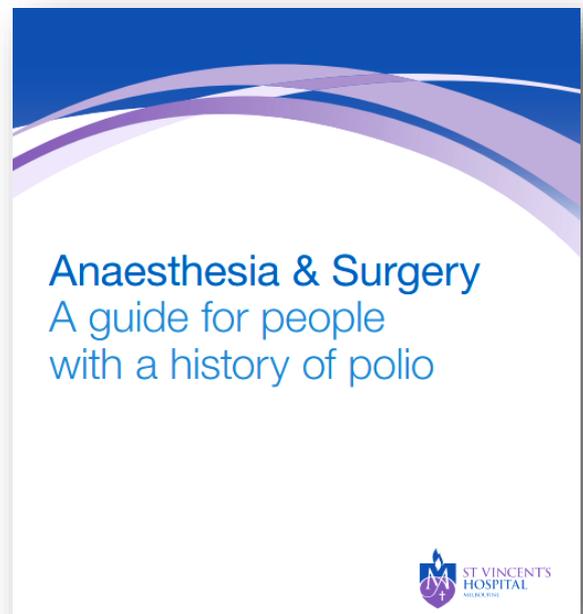
Anaesthesia & Surgery Guide

Anaesthesia & Surgery A guide for people with a history of polio

Polio Services Victoria, a service of St Vincent's Hospital, Melbourne (Australia) has developed a comprehensive new guide which can be viewed and/or downloaded from their website [here](#).

People with a history of polio have special needs when it comes to anaesthesia and surgery. This guide is for anyone who has had polio and will be having surgery. It has information to help you and your healthcare team plan your surgery. Take it with you to any appointments before you have surgery, and when you go into hospital.

Polio Services Victoria is a multidisciplinary team comprising a rehabilitation medicine physician, a physiotherapist, an occupational therapist, an orthotist and a social worker. They provide a specialist assessment and referral service, with limited capacity for direct treatment/therapy. 🌟



LEoP Clinical Practice Workshop Series Update

By Mary-ann Liethof
National Program Manager

Polio Australia partnered with [Rotary International District 9685](#) to stage seven **free** Post-Polio Clinical Practice Workshops throughout the Blue Mountains and North Western Sydney between November, 2015 and April, 2016. These Workshops were facilitated by [Melissa McConaghy](#), neurophysiotherapist and Principal of [ARC Health](#), based in St Leonards, NSW. Melissa is a member of Polio Australia's Clinical Advisory Group, and will be presenting at the [Australasia-Pacific Post-Polio Conference](#) in September. We also engaged Jennifer McConaghy, administration assistant at ARC Health, to provide admin support.

Rotary District 9685 secured funding through their Clubs to pay for Melissa and Jennifer's time, and project costs. Polio Australia supplied brochures, hard copies of "The Late Effects of Polio: Introduction to Clinical Practice" book, a PDF of "The Late Effects of Polio: Managing Muscles and Mobility", and a Certificate of Participation for 2.5 hours of Professional Development points.

The participating Rotary Clubs secured the venues, organised refreshments, and liaised with Jennifer regarding logistics, including dropping flyers into local health service providers.

The program was developed following preliminary discussions with John Tierney at a 2015 District Conference in Cessnock, NSW. Polio Australia had conducted a successful trial clinical practice workshop in Melbourne in 2014, and was seeking support to organise a further series of workshops to share resources and training for health professionals.

At the beginning of the 2015/16 Rotary year, the incoming District 9685 Governor, Gina Growden, was briefed on the discussions with Polio Australia and immediately supported the proposed series of Workshops. The Governor shared the concept with her Clubs and District leaders and agreed that the project had great potential to be further developed by Rotary International and play a role in the culmination of the Polio Plus campaign. It was emphasised that the proposed program had a strong 'fit' with Rotary's vocational base.

Over a six month period, seven workshops were run in: Ryde, St Leonards, Katoomba, North Rocks, Penrith, Hornsby, and Gosford.

Another has since been rescheduled for Windsor on the 28th of June. Polio Australia has secured the services of Catriona Morehouse,



Physiotherapist, [Post-Polio Clinic at Mt Wilga Private Hospital](#) to facilitate this Workshop, using the same presentation used by Melissa. More details and bookings [here](#).

The 130 health professionals who attended included: general practitioners, community health workers, exercise physiologists, massage therapists, nurses, occupational therapists, orthotists, physiotherapists, social workers, and a speech therapist. Participants came from a variety of work areas: public and private sectors, students, private practice, and even several retired practitioners.

Very positive written feedback was received from the majority of health professionals who took part in the workshops and these comments are being collated for future use, and will be presented by Mary-ann Liethof at the Australasia-Pacific Post-Polio Conference in September. It is hoped that a number of the Workshop participants will also attend the Conference.

Discussions are now under way for a similar program of Workshops to be facilitated in New Zealand by Julie Rope, a neurophysiotherapist who runs her own rehabilitation clinic in Auckland. Julie is working together with Polio NZ, and is being funded by the Duncan Trust to educate health professionals in the late effects of polio.

In her handover dinner, District 9685 Governor, Gina Growden, recorded the appreciation of her Rotary District and Rotarians in general for the outstanding support and commitment from all associated with Polio Australia and ARC Health, including the dedicated band of polio survivors who provided invaluable insight at every workshop: Gillian Thomas, Sue Ellis, Rosemary Cantwell, Merle Thompson, Anne O'Halloran, Di O'Reilly, Ben Tipton, Di Bull, Wayne Woolley, and John Tierney. ●

Supporting Polio Australia

Polio Australia would like to thank the following individuals and organisations for their generous support from 1 March to 30 April 2016.

Hall of Fame

Name	Donation
Jill Pickering	\$4,000
Rio Carnivale Party*	\$1,450.00
Total—\$1,850.00	

*More to come in May

General Donations

Names				
Anthony Brain	Jill Burn	Katherine Guthrie	Hume Polio Self Help Group	
David Miller	Rotary Club of Albany Creek	Royal Overseas League	Liz Telford	
Total—\$768.20				

Facts You Need To Know About The Charity Sector

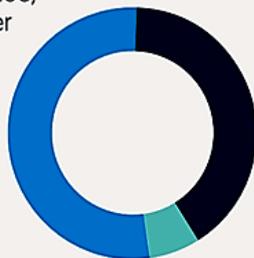
- ♦ Australia has around **54,000 Charities**, employing over **1M staff** and an annual income of **\$104B!**
- ♦ The largest **5% of Charities**, receive **80%** of the **sector's income**
- ♦ **64%** of **Australian Charities** receive **no Government Grants**
- ♦ Charities received **\$6.8B in donations and bequests** in 2014
- ♦ **31.5%** of Charities have **less than \$50,000 income** and **44%** operate with **no paid staff**
- ♦ The average age of a charity is **33 years** and **6%** are **over 100 years**
- ♦ **80%** of Charities **use volunteers**
- ♦ **64%** of Charities are **classified small**, **17% medium** and **19% large**

- Culture and recreation (6%)
- Development and housing (8%)
- Education and research (18%)
- Environment (3%)
- Health (9%)
- International (1%)
- Law, advocacy and politics (1%)
- Other/Unknown (11%)
- Philanthropy (6%)
- Religion (30%)
- Social services (7%)

● **\$54.5 billion** is from other income and revenue, including sales, member fees and user pays

● **\$42 billion** is from government grants

● **\$6.8 billion** is from other donations and bequests*



Statistics from Centre for Social Impact & Social Policy Research

Polio Australia is a typical 'small charity', receiving no Government Grants, with only one full time paid staff member, and many volunteers.

We thought it was interesting that 64% is the same statistic used for both the number of Australian Charities receiving no Government Grants, and those classified as 'small'.

Unlike larger charities, Polio Australia relies on your donations and bequests to do its work. Please consider supporting our 'small charity'—tax receipts provided for donations over \$2.00. ●

64% had no income from government grants

* Donations contribute to: **13%** of total income for large charities, **23%** for medium charities and **32%** for small charities

DONATE

Request Information

Rio Carnivale Fundraising Party!



Rio came to Brisbane on Sunday the 15th of May thanks to Sue Mackenzie's Rio Carnivale Fundraising Party! Around 70 people attended the Brunswick Hotel to enjoy tapas, entertainment by the [SAMBALISCIOUS Dancers](#) direct from Rio, and a fashion parade by [SFH Designs](#). Sue and her team of volunteers organised the day, with generous sponsorship from [Gold Coast Benji](#), SFH Designs, [Red Works](#), and [Elliotts Accounting](#). Sue was kept busy announcing competitions and drawing over 30 raffle prizes. The total nett amount raised for Polio Australia was an amazing **\$7,821.67**—and a very good time was had by all! A big **THANK YOU** to Sue, and everyone who contributed to making the day such a wonderful success. Riba! Riba!! 🌟 - Ed

A note from Sponsor SFH Designs By Sarah Hutson (Owner)

Wow what an afternoon of colourful fun, dancing and, most importantly, fundraising! Our Rio Carnivale Party Fundraiser was a fabulous hit with everyone! Starting with the amazingly talented Sambaliscious dancers direct from the Rio Carnival 2016, in their feathers and sequins, dancing up a show-stopping storm. Our SFH Designs Fashion Parade showcased our colourful and exquisite designs from around the world. While our wonderful host Sue kept the fundraising happening with loads of raffles, lucky door prizes, silent auctions and donation request competitions. There was of course, a lot of hard work behind the scenes, with all the table floral arrangements including cut-out parrots and flamingos, table menus, a supply of pineapple lollies and table numbers, all personally made and sponsored by SFH Designs. We also had a SFH Designs Pop-Up Shop on the day, from which we donated an extra 20% of our sales (\$300).

Overall we were very pleased to have been able to help Sue achieve her fundraising target. Oh, and Sue is also my mum - what an amazing mum I have!

www.sfhdesigns.com.au
Instagram: SFH_DESIGNS
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*Sambaliscious Dancers with Sue Mackenzie (back)
Mary-ann Liethof, and John Tierney*

More photos can be viewed on [Facebook](#). 🌟



Why Are Core Costs Important?

By Gillian Thomas, Polio Australia's Vice President and Business Manager

Polio Australia's [2015-2018 Strategic Plan](#) details its priorities over that period. The priorities have been developed in line with the Objects of the Polio Australia Constitution.

In order to achieve the objectives of the Strategic Plan in support of polio survivors, Polio Australia must develop its financial and human resources to ensure that both its core costs and its program costs can be met, and to ensure that planned programs, projects and activities are successfully undertaken.

Core costs are the expenditure items that are not connected with the levels of activity undertaken by an organisation. They are the awkward costs that are difficult to associate with any specific outputs, as they will exist *before* and *after* a project has been running. Core costs include governance, management and staffing, together with support costs such as office rent, admin and bookkeeping, communications and websites, and publications and promotion. Why are core costs important? These costs will always need to be funded, whether an organisation is running 30 projects or just three. They're fundamental to Polio Australia's survival, but can't be directly associated with any specific outcome. As such, it is very difficult to attract government or corporate funding towards these costs.

Polio Australia and the services it is able to deliver to benefit polio survivors are currently necessarily limited in scope and severely hampered by a lack of financial and, it follows, human resources. The lack of government or other recurrent funding means ongoing efforts must be put into raising funds to enhance and expand the organisation and its services through avenues such as one-off project grants, Rotary relationships, bequests, and donations.

In essence, tax-deductible donations are the life blood of Polio Australia's existence – and they need not be large. Donations can be viewed as blood transfusions – every precious drop is needed. As well as appreciating an end-of-financial-year donation, regular smaller donations are just as gratefully received.

Did you know that you can set up a recurring withdrawal from most internet bank accounts to make your donations automatically at the times you choose (for example, monthly or quarterly)? Just be sure to [let us know](#) the deposit details and we will email you our official receipt each time, then at the end of the financial year we will also send you a statement of your donations throughout the year, to help in preparing your tax return. 🍎

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Australasia-Pacific Post-Polio Conference Update

Have you Registered for the Australasia-Pacific Post-Polio Conference yet?

After 18 months of planning, the Conference is now only a little over 3 months away, so make sure you secure your booking for this unique international event soon.

Polio Australia is privileged to have access to the skills, experience, and knowledge of so many post-polio experts at this Conference. There are an unprecedented 54 separate speakers, and 6 poster presentations, with many of the presenters delivering more than one paper.

Apart from 35 Australian physicians and 'lived experience experts', presenters will be arriving from Denmark, India, Italy, Japan, the Netherlands, New Zealand, Spain, Sweden, the UK, and the USA. Several delegates are also attending from these countries, with the addition of Belgium, Georgia, Malawi, and Pakistan, providing a truly global overview.

Confirmed major sponsors to date include: NSW Health, GSK, and ResMed, with several more under negotiation. Sponsorship packages can be viewed [here](#).

REGISTER NOW

Polio: Life Stage Matters

Polio Australia is tackling the challenge of enhancing the knowledge base of health professionals in relation to the post-polio body by running the first ever [Australasia-Pacific Post-Polio Conference – Polio: Life Stage Matters](#). The Conference is being held at The Four Seasons Hotel in Sydney from 20-22 September, 2016.

In the past 6 months, 130 multi-disciplined health professionals have attended a series of Post-Polio Clinical Practice Workshops across Sydney.

Here are 5 outcomes the participants reported in their feedback:

1. I work with aged care facilities and we often have polio survivors. My follow-up action is for more self-education and awareness of my patients.
2. I will be including post-polio in my PT assessments, and I am very interested in educating our surgeons on the dangers/detriments of anaesthetics.
3. I have post-polio clients who I considered during the presentation. Amazing to hear the personal accounts – very powerful!
4. Working in physio private practice I see the occasional patient with the late effects of polio. I now have much more information to think about and am more aware of appropriate management and referral.
5. I knew so little about this topic and now feel inspired to learn more!

The late effects of polio affects thousands of Australians, with many unable to find health practitioners with sufficient knowledge to treat them. Make sure you are informed in the provision of gold standard, appropriate care required by your post-polio clients.

This Conference promises 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 current [Program](#) and [Abstract Summaries](#) are now online and will be published in a special edition of the [Journal of Rehabilitation Medicine](#). 🌐

- Ed

Did you know?

- Registration options are available for 1, 2, and the full 3 days of the Conference.
- Health professionals are currently being offered a **group discount** when they book for 3 delegates, with the 4th one free.
- Day 3 of the Conference [Program](#) comprises 8 x 2 hour Master Classes for health professionals on a variety of post-polio conditions.
- Full registration includes free entry to the Welcome Cocktail Party and networking function on Day 1 at the [Museum of Contemporary Art](#).

Contact melanie@intermedia.com.au / 1300 789 845 (Australia) / +61 2 8586 6103 (international) to find out more.



Establishing Post-Polio Clinics in New Zealand

By Julie Rope, PT

Until recently polio survivors in New Zealand have had little support to either be assessed for the Late Effects of Polio (LEoP) or develop clinically robust rehabilitation plans. In 2015 Polio NZ developed a strategic plan with the development of polio clinics in NZ as a major goal. Gordon Jackman was hired by Polio NZ in November 2015 to implement the strategic plan.

At the same time the Sir Thomas and Lady Duncan Trust, founders of the Duncan Polio Hospital in 1945, had initiated a process with Julie Rope of [Rope Neuro Rehabilitation](#), Newmarket, Auckland, with similar aims. Polio NZ, the Duncan Trust and Julie Rope got together and developed a plan to create a clinical support network in New Zealand for polio survivors, wherever they were, to enable them to access expert assessment and supported rehabilitation plans, as well as ongoing support for them and their families.

It is considered that there is a mix of quality and experience of clinicians who have worked with polio survivors and a potential dilution of support across geographically wide areas. This limited ability to access expert assessment reinforces the lack of clinical practitioners who understand the management of polio and who understand the issues associated with the ongoing support for polio survivors and their families. There are currently no training programmes within New Zealand either at an undergraduate level or in care related employment and professional body education programmes.

The vision for the future would involve polio clinics in Auckland and at QE Health in Rotorua, with further clinics planned for Wellington, Christchurch and possibly Dunedin. Connecting all these clinics will be a virtual centre of excellence which will share resources, co-ordinate the training of clinicians and health professionals, and resource support in the home.

Conducting clinics in remote areas is also an aim, as many polio survivors have great difficulty in travelling to main centres.

Measures taken so far include initiating an epidemiological study of polio survivors in New Zealand with Auckland University of Technology to inform realistic discussions with District Health Boards (DHBs) on the provision of services. We have met with Ministry of Health (MoH) officials in Wellington about our proposals, receiving a very understanding hearing and ongoing support.

Polio Australia hosted Julie Rope at an "Understanding the Late Effects of Polio Clinical Practice Workshop" at Mt Wilga private hospital and have supported her with resource material so that she can deliver the workshops in New Zealand and in the future develop educational resources and webinars. Catriona Morehouse from Mt Wilga has been very generous in sharing her experiences with us. Other steps have included meeting with DHB directors to establish current DHB's level of provision for polio survivors with the LEoP and opportunities for collaboration in the future.

Julie Rope plans to open "The Clinic for Neuro Muscular Conditions" at her Balmoral, Auckland, neuro physiotherapy establishment which will initially focus on the assessment of the late effects of polio and the provision of rehabilitation plans for polio survivors. Julie plans to eventually expand the clinic to cater for a wider range of chronic Neuro Muscular Conditions.

She is interested in compiling a network of educated therapists with an interest in the management of people with the Late Effects of Polio and clinical expertise/resources to provide consistent assessment and relevant management/treatment.

If you would like to register your interest in the development of this polio clinic network project [in NZ] please contact Julie Rope via admin@ropeneurorehab.co.nz.

Former Duncan Hospital polios gather to celebrate

Over 600 people gathered on a Rangitikei farm near Hunterville to launch a new book "Otiwhiti Station", the story of the Duncan family.

Many Polio survivors owe their recovery to the Duncan Hospital, which was started by Mr & Mrs T.A. Duncan and funded from the proceeds from the Otiwhiti Station farm in the 1940s and 1950s.

Source: [Polio NZ 2011 News](#)



Post Polio Syndrome



What is it, and why does it matter?

By Ted Hill, CEO of The British Polio Fellowship

Source: www.hippocraticpost.com
—13 May 2016

Poliomyelitis, or Polio, as it is more commonly known, is one of the world's best known diseases. Having famously been contracted by Frida Kahlo, Neil Young and even Franklin Roosevelt, Polio was endemic throughout much of the 20th Century. However, one of the most successful vaccination campaigns in history has all but seen off Polio, with just 74 cases recorded last year, and just Afghanistan and Pakistan left as Polio endemic countries.

While the vaccination campaign is undoubtedly a huge triumph for medicine, the battle against Polio is not yet won. Members of the public and medical professionals alike are now unfamiliar with the symptoms of Polio and when it comes to Post Polio Syndrome (PPS) even less so.

Post Polio Syndrome is a badly misunderstood condition. Just seven per cent of the UK public have heard of PPS. That's despite 120,000 living with PPS in the UK today – a similar number to Parkinson's, which 86 per cent of the public are familiar with. Even more alarmingly, this lack of awareness also translates to the medical profession, where just 55 per cent of GPs feel able to diagnose the condition, and 18 per cent of GPs did not know how to manage the fever, fatigue, pain and breathing difficulties which characterise the condition when it is diagnosed.

A large part of my job as CEO of The British Polio Fellowship is to try and spread awareness of Polio and PPS – both among the medical profession and the public at large. Given that 80 per cent of people who have had Polio are likely to contract PPS, it is an important job both now and for the future, both here in Britain and abroad.

PPS symptoms include cold intolerance, increasing weakness, muscle and joint pain, stamina problems, sleep disturbance, breathing problems, swallowing problems, fatigue and pain. As you may notice, many of these symptoms cross over with other conditions, causing real problems with misdiagnosis, something which is only compounded by the similarity of the symptoms to common signs of ageing. Matters are made even more confusing by the similarities between PPS and Chronic Fatigue Syndrome, a condition which it shares much in common with.

Diagnosing PPS can therefore be extremely difficult, with symptoms often hard to separate from complications arising from the original

infection. There is no laboratory test for PPS, nor are there any specific diagnostic criteria. Instead, three key criteria are required to diagnose PPS: previous diagnosis of Polio, long interval after recovery and the gradual onset of weakness.

When PPS is finally diagnosed, there is no silver bullet or magic treatment. Instead, PPS can only be managed. While this outcome is not perfect for those living with the condition, much can be done to alleviate the pain it causes, as properly managed, PPS may stabilise or only progress slowly. Much can be done to retain independence, including appropriate treatment for symptoms, self-management strategies such as pacing and energy management, appropriate use of adaptive equipment, looking after your general health, and social and emotional support.

Currently, there are no UK specific guidelines to managing PPS, which means that access to appropriate services for people with PPS can vary greatly. To help combat this problem, The British Polio Fellowship produced a new document entitled [Post Polio Syndrome: A Guide to Management for Healthcare Professionals](#). This ground-breaking document is the first of its kind, and was produced with assistance from leading experts in the field. I hope it signals the start of a better understanding of PPS, and if just one person receives better care as a result of that document, then it will have done its job.

With the aforementioned document, and campaigns such as PPS Day, which we also run, The British Polio Fellowship take a two-pronged approach to PPS, providing both practical advice to members and helping to spread awareness of the condition. As time goes on, we are likely to see more and more people living with PPS, particularly in the developing world. I hope that by then, we will have made some serious headway into making the world aware of what has become the forgotten footnote of Polio. While Polio is one of the world's most recognised diseases, PPS sits in the shadows – and yet the reality is now, that PPS causes much more pain and suffering. The battle against Polio may be all but over, but the war is not won. It is now time for us all to focus our efforts on tackling, managing and understanding PPS.

Ted Hill, MBE joined The British Polio Fellowship in 2012 from a strong Third Sector background. Having worked in the voluntary sector for over 35 years, Ted was awarded an MBE for his services to the Voluntary & Community sector in the 2011 Queen's New Year's Honours. Prior to joining The British Polio Fellowship in 2012, he worked for Hillingdon Association of Voluntary Services.

Refining The Portrait of Late Effects of Polio

By Phil Stevens, MEd, CPO, FAAOP

Content provided by [The O&P EDGE](#)
—February 2016



I treat fewer patients with post-polio syndrome (PPS) than I used to. I suspect this is true for most clinicians who have a decade or two of clinical experience. As practitioners see progressively fewer cases of PPS, we are less able to evaluate a given case within a broader perspective of how this patient population generally presents and the extent of the disease's effects on things like muscle strength, gait performance, balance

and fall history, and activity levels. Clinicians, particularly newer clinicians, may never see enough cases to independently develop an accurate, comprehensive portrait of what the late effects of polio look like.

Fortunately, there are centers that still manage large numbers of patients with PPS. One of these, a rehabilitation clinic based in a university hospital in southern Sweden, maintains a database of over 300 cases. Researchers from this center have published a series of studies to describe a more complete portrait of patients who have mild to moderate PPS. This cohort is defined as individuals between 50 and 80 years of age who are able to walk at least 300 meters with or without assistive devices or lower-limb orthoses, but do not require a wheelchair as their primary means of mobility. This article summarizes some of those findings and refines the portrait of post-polio effects.

LOWER-LIMB ORTHOTIC USE

Early in my career, a mentor described a conversation he overheard in a hospital when a surgeon's rationale for performing a surgery was questioned. "Because", the surgeon tersely responded, "when you're a hammer, everything looks like a nail". I've always retained this conversation as a reminder that we are products of our collective experiences, and that these experiences may or may not accurately represent the bigger picture. Just as an experienced cranial orthotist might inaccurately assert that conservative repositioning will never adequately address deformational plagiocephaly because such corrected cases simply don't present in the

clinic (and why would they?), it would be easy for the orthotic community to conclude that because we ultimately brace almost every case that is referred to us for treatment, most patients with PPS utilize lower-limb orthoses. However, this does not appear to be the case.

For example, in a random selection from the Swedish database of 102 cases with a response rate of 79 percent, only 21 of 81 cases used lower-limb orthoses—with AFOs outnumbering KAFOs roughly 4 to 1. Similar numbers were observed in a separate cohort of 122 individuals extracted from the same database. Interestingly, this lower-than-anticipated use of lower-limb orthoses may not be entirely due to a lack of need. In a third trial, examining the relationship between muscle strength and gait performance, the strength of the more affected knee extensors were, on average, 35 percent weaker than the less affected extensors. More strikingly, the more affected dorsiflexors were, on average, 62 percent weaker than the less affected dorsiflexors. In fact, more than half of the 90 subjects included in the study had no measurable strength in the dorsiflexors of at least one limb, yet only 21 subjects walked with an AFO. Given the diligence with which these subjects have been managed within the rehabilitation clinic, this discrepancy would appear to be one of choice rather than a lack of access. Many patients in this population who might reasonably benefit from lower-limb orthoses choose not to use them.

Read more [here](#).

SUMMARY

When the Swedish data is viewed collectively, a composite portrait of PPS begins to emerge. It is a tremendously variable patient group frequently presenting with muscle pain, weakness, and fatigue. Despite the obvious potential benefit of lower-limb orthoses, many individuals choose not to pursue these interventions. Mysteriously, muscle weakness is only moderately correlated to gait performance measures, with greater correlations associated with walking endurance and elevated walking speeds. Impairments, limitations, and concerns about falling are frequently reported, yet this patient population generally remains fairly active compared to other populations of older adults. Of this activity, nearly three-quarters is done in and around the home.

This portrait allows practitioners to better assess how individual patients with PPS fit within the broader post-polio population and may guide clinicians to better predict and address areas of concern and limitations. ●

A Polio's Day Starts Hard

**By Peter Willcocks
—May 2016**

*Sleep deprived
we sit for a bit.
Tic Toc,
getting up
bit by bit.*

*Arms and legs are toxic,
chest heavy to breath,
rasping throat to swallow...*

*Groan to shower, stretch to dry,
drag clothes on and sigh.
Braces time...*

*Shoes, socks, pickup sticks,
shoe horns, steps and braces
all aligned,
just as pets
ready to play.*

*struggle...struggle...struggle...
sock it to me... sock it to me...
Exhausted, we start each day.*

*Gobbling experts'
antidepressant pain relief
just makes me.... urrh
Drugs can't dress me.*

*Daily we build
the pain, the frustration
and too often we despair.*

*Please DHHS¹ and PSV²
don't SWEP³ us away.
New braces. Now please.
Not in two years' time.*

*and please don't tell us
we need backup aids
when we're already
waiting on a list.*

*and please don't tell us
what can't be done.
Spend time in our homes,
start where the pain begins.*

*Burning out,
ageing too soon,
many things become
just out of reach.*

*Bring cups and fillers
to hand.
Change taps and knobs
to push 'n pull.*

*Health check our chairs and
things
Guide us to the manageable.
Reassure our carers, partners
and friends.
That there's lots of living
yet to do.*

*and please don't make us feel
a burden,
polio wasn't a choice of ours.*

*Work with us for dignity,
Work with us as a whole.
Work with us to share
your world
our world
for all of those who need.*

¹ Department of Health and Human Services (Victoria)

² Polio Services Victoria

³ State Wide Equipment Program (Victoria)

Sister Kenny Clinic in Newcastle

After 70 years of neglect, Alastair and Diane Kinlock decided to buy and restore an old historic building in Newcastle East (NSW), known as the *Cotts Sailors' Home*. Through the Heritage Impact Statement, they discovered the home was formerly used as a Sister Kenny out-patients clinic, which they knew would be of great interest to their friend, Dr John Tierney (President of Polio Australia). Excerpt follows:

Sister Kenny Clinic: 1936-1943

Following the decision not to go ahead with the accommodation of chronic invalids at the Coutts' Memorial Home, the Board of the Newcastle Hospital considered a proposal to establish the Home as a trial clinic for the treatment of infantile paralysis based on the methods adopted by Sister Elizabeth Kenny.

By June, 1938 an average of 75 patients were treated daily at the Sister Kenny Clinic. The clinic continued to function to capacity the following year by which time sufferers of infantile paralysis were also being treated at the Infectious Diseases' Hospital at Waratah. In 1940 the sister Kenny Clinic came directly under the control of the Newcastle Hospital and was subject to the same authority and discipline as other units of the Hospital. A decision was made in 1941 to move the treatment of all infantile paralysis cases to the Infectious Diseases' Hospital, Waratah.

Follow the restoration progress on the *Cotts Sailors' Home* blog [here](#).



NSW Wheelchair Users Get Increase In Taxi Subsidies

By Kimberley Martin

It's good news for wheelchairs users travelling in NSW taxis with support payments increasing from July 1. The increase is part of a \$15.5 million boost to deliver more accessible services and applies to both eligible Taxi Transport Subsidy Scheme (TTSS) customers and drivers of Wheelchair Accessible Taxis (WATs). The NSW Government has been reviewing all transport options for people with disability and part of the

reform package includes a reduction in a lot of red tape around taxi travel, namely an increase in the taxi subsidy paid to passengers with disability that has now doubled to \$60. WAT incentive payments will be doubled too, up from \$7.70 to \$15 for each pickup. License fees, which were previously an expensive annual cost, have been abolished along with the booking service fee.

Read full **Freedom2Live** article [here](#).

New Disability Discrimination Commissioner

Source: [Disability Australia Media Release](#)
—6 May 2016

Disability Australia Embraces the Appointment of the New Disability Discrimination Commissioner, Alastair McEwin

National people with disability organisations have embraced the appointment of the new Disability Discrimination Commissioner, Alastair McEwin.

Disability Australia congratulates the Attorney General, Senator the Hon George Brandis QC, for the appointment of a dedicated Disability Discrimination Commissioner.

"We welcome the new Disability Discrimination Commissioner, Alastair McEwin", said Matthew Wright, CEO of AFDO and spokesperson for Disability Australia.

"Alastair is one of us, he is a person with a lived experience of a disability (deaf) who is well regarded and from our communities".

"We know that he has a strong and extensive advocacy background, appreciates the diverse challenges we face and will continue to act in the interests of all people with a disability." said Mr Wright.

Alastair served on the Board of Deaf Australia; is the President of the Deaf Society of NSW; Chairman of the Disability Council of NSW; is the current Executive Director of Community Legal Centres (NSW); is the former CEO of People with Disability Australia and was the former Manager of the Australian Centre for Disability Law.

We still have a long way to go in realising the human rights of all people with disabilities and it is great that the government have appointed a full time Disability Discrimination Commissioner with a lived experience to realise equity for all people with disability.

"This is a good appointment by the government, a good appointment for people with disability and our organisations look forward to supporting Alastair in his new role in any way we can". ●

NDIS (Not Damn Interested In Seniors)



Lori Grovenor writes that she first became engaged in this issue through her own interactions with the aged care system as a person with disability. Her experience has been frustrating, undignified and complex and it concerns her to think how many people are likely to fall through the cracks in the future should these issues remain unresolved. To this end, Lori has assisted in the development of a grass roots advocacy campaign entitled **NDIS (not damn interested in seniors) = My Aged scare**. View a copy of the campaign briefing paper [here](#), which provides further details about proposed solutions to the following problems, as well as information about Australia's human rights obligations to older people with disability

The background:

In 2013, the government commenced rollout of the National Disability Insurance Scheme (NDIS) – a lifetime scheme of care and support for people with disability. But people who acquire a disability after the age of 65, or are over 65 when the scheme rolls out in their area are not eligible for the NDIS. These people are instead expected to access the support they need through the aged care system, through a gateway called My Aged Care.

The problems:

Lack of information: Many people with disability have had no interaction with the aged care system and are largely unaware of how it operates. Federal and state governments continue to inject significant amounts of money into projects that are designed to inform people with disability about their rights under the NDIS, but there has been no information provided to people with disability who are over the age of 65 to inform them about My Aged Care as it relates to the specialist support needs of people with disability. As a result, many people are falling through the cracks.

Hefty co-payments: Under My Aged Care, older people with disability are asked to make co-payments towards any services or supports they require. This requirement is unique to My Aged Care and does not apply to people accessing supports under the NDIS. Although co-payments were originally intended to be dependent on an individual's income and assets, it appears that

NDIS (Not Damn Interested In Seniors) (cont'd from P13)

this policy is not being honoured. The services and supports that are required by people with disability can also be far more cost-prohibitive than those of the average older person, making their cost of living significantly higher.

Lack of understanding of the specialist needs of people with disability: The aged care system was set up to accommodate the needs of people experiencing deteriorating health due to aging—not people with permanent and profound disability. As disability is the core business of the NDIS, staff at the National Disability Insurance Agency typically have a high level of empathy and disability awareness. The same cannot be said for the staff at My Aged Care who are largely unfamiliar with the broad spectrum of needs with

which people with disability may present .

In order for Australia to be considered to be meeting its international human rights obligations under the *Convention on the Rights of Persons with Disabilities*, there must be equality of support for all people with disability, regardless of factors associated with age.

Source: Email from Lori Grovenor—16 May 2016. View more on [Facebook](#) and [My Aged Scare](#) website.

Additional information on NDIS and Aged Care inequality can be seen on the *My Disability Matters* website [here](#).

7 Secrets No One Told Me When I Learned To Meditate

By Kristy Rackham, RN

Meditation doesn't have to be hard if you understand a little about what it is, and what to expect! I started meditating and teaching meditation at age 20 when experiencing a spontaneous spiritual awakening and opening of my third eye. My spiritual teachers were 'not of this world' and so they were not able to help me with the nuances of a meditating human body and mind in the 3rd dimension! For me, opening to the enormous psycho-emotional and physical benefits of meditation was easy and immediate. However, establishing a regular practice was a little more difficult as it came with a whole host of belief systems and doctrines that no one could explain for me. I trust that these 7 secrets that no one told me when I learned to meditate will help you hone and enhance your practice and help you cut to the chase and help you get the most out of your meditations.

1. Your body will play up. It will wear you down like a small child on sugar and will not want to stay still for more than a few seconds before a random collection of aches, pains, itches and scratches kick in to grab for your attention. This is all OK and perfectly normal! It is not a sign that you're doing it wrong or are "no good at meditation". In this very fast paced world of ours, we have forgotten that being relaxed and peaceful is actually our natural state. A guided meditation can help you to focus and also teach you how to work with the body instead of against it.

2. You don't have to meditate like a Zen monk. Sitting with an Indian Guru and 'Ohm-ing' for hours on end really also isn't the most efficient way to make a difference to your wellbeing. Scientific studies now show that as

little as 10 minutes of meditation each day will have a beneficial effect on your entire being. It doesn't even have to be a sequential 10 minutes. In fact, the harder you try, the more resistance you create in your body and mind. This then contributes to greater stress levels and dis-ease! Just relax - Meditation can be very straight forward if you let it.

3 Meditation is not a team sport. It is an intensely personal, precious, quiet moment within your day that you get to be still and take the pressure off. The content of your meditation doesn't need to be shared, it isn't a competition, and it doesn't matter what someone else thinks of it. This is because it comes from YOU and your unique divine expression of the Universal energy - you're one of a kind, so please don't judge your 'brand' of meditation by other people's standards.

4. Meditation is not spiritual Hoo Har. It's also not about making yourself permanently blissful and walking around in a state of eternal ecstasy (although glimpses of that is definitely possible!). If anyone tells you they don't have any issues now that they're meditating, they're probably in denial. Meditation is a practical, perfectly natural method of enhancing body, brain and spiritual function getting in touch with your creative potential. From there you can take actions that bring you greater peace, strength, resourcefulness and wellbeing than you've ever experienced before.

5. Meditation gives you access to the 'real you'. The benefit of this is that you can begin or expand your ability to live consciously, purposefully and from a truly authentic place. For this reason, it can sometimes be very confronting and a not a little bit scary at times! We can

7 Secrets No One Told Me (cont'd from P14)

discover elements of ourselves that have previously been denied or hidden. This is a BLESSING when embraced for the gift that it is! Once seen, limitations can be cleared or transformed opening the way for a happier and more joyful life than you can possibly imagine.

6. You can't 'do it wrong'. I REALLY wish someone had told me this when I began. I might have better spent the energy I wasted on guilt and self-punishment! But hey, that was also part of my journey! Although Meditation is not something that you can make a mistake with, it becomes easier and the body and mind relaxation response becomes faster with practice, like everything! It is also worth noting that no two meditation experiences will be exactly alike – therefore, it is impossible to judge a meditation as good or bad without limiting your experience. Accept every meditation as it comes to you and trust that everything is exactly how it is meant to be right now for your highest evolution.

7. There is no single BEST way or better style of meditation than another – they all have merit and purpose. Although it can be said that certain meditation styles work particularly well for certain people, or certain circumstances. For example, guided Mindfulness and Creative Visualisation meditation are great for first timers. Mindfulness can help to manage out-of-control thoughts and switch off the fear centre of the brain to bring about an instance physiological relaxation response. Creative visualisation is great for beginners as it utilises our imagination – something that is usually pretty active in most people – to imagine positive outcomes and future experiences that we wish to bring about in our life.

Sometimes, taking the first step to start meditating is the most difficult. If you always wanted to try it, but perhaps you didn't think you'd be able to do it, or maybe it's not easy for you to attend a group class, you may find a private guided meditation lesson is a great place to start.

In a private session you will learn how to break through any beliefs that are stopping you from getting the most out of your meditation. You'll be able to hone in on any specific life challenges that are bothering you or weighing you down and get immediate relief, and I'll be there to guide you the whole way, which will help you to anchor your mind, reign in a restless body and really tap into your true personal power. We also record your live guided meditation for you to keep! A personalised meditation that is exactly customised to your needs can be used to practice your meditation skill as often as you like at home. Better still, you can come to the clinic and meditate with me in person, or via Skype if you're somewhere else in the world!

Do you want to learn to meditate but can't get to a group class?

Do you want to focus on a specific personal issue in a meditation but have trouble guiding yourself through it?

Are you interested in how meditation can help you manage chronic illnesses like pain and fatigue?

Find out more at www.myholisticnurse.org or call 0487 769 629. 🌐

Panadol Osteo To Remain Delisted

Source: [Pain Australia Newsletter](#) – May 2016

The Pharmaceutical Benefit Advisory Committee (PBAC) has restated its decision to delist Panadol Osteo from the PBS. The PBAC says it assessed the issues raised by stakeholders including the Pharmacy Guild and PainAustralia, but did not consider there was any basis to revisit earlier recommendations.

"The decision will be disappointing for many people who regularly rely on Panadol Osteo as the first line treatment for osteoarthritis", says PainAustralia CEO Lesley Brydon. "It is generally regarded as the least harmful option, and it is quite likely that patients, especially those on a concession, will ask their doctor for alternative PBS subsidised medication to help manage their pain, including low dose opioids".

An analysis by the Guild last year reported that on the PBS, two packs of Panadol Osteo for a patient with a concession card was \$7.52 a month, which equated to \$90.24 a year and less if the patient reached their Safety Net during the year.

Following the delisting the price increased to \$14 a month, or \$168 a year, and it no longer contributes to Safety Net eligibility.

The PBS says the active ingredient in Panadol Osteo can also be found in the immediate release form of paracetamol, which can be purchased more cheaply. However, it is the more convenient, sustained release formulation that made Panadol Osteo a drug of choice for many people with osteoarthritis. 🌐



Effectiveness of NSAIDs

Bruno R da Costa, PhD[†], Stephan Reichenbach, MD[†], Noah Keller, MMed, Linda Nartey, MD, Simon Wandel, PhD, Prof Peter Jüni, MD, Dr Sven Trelle, MD

Source: [The Lancet](#) – 17 March 2016

Effectiveness of non-steroidal anti-inflammatory drugs for the treatment of pain in knee and hip osteoarthritis: a network meta-analysis

Summary

Background

Non-steroidal anti-inflammatory drugs (NSAIDs) are the backbone of osteoarthritis pain management. We aimed to assess the effectiveness of different preparations and doses of NSAIDs on osteoarthritis pain in a network meta-analysis.

Methods

For this network meta-analysis, we considered randomised trials comparing any of the following interventions: NSAIDs, paracetamol, or placebo, for the treatment of osteoarthritis pain. We searched the Cochrane Central Register of Controlled Trials (CENTRAL) and the reference lists of relevant articles for trials published between Jan 1, 1980, and Feb 24, 2015, with at least 100 patients per group. The prespecified primary and secondary outcomes were pain and physical function, and were extracted in duplicate for up to seven timepoints after the start of treatment. We used an extension of multivariable Bayesian random effects models for mixed multiple treatment comparisons with a random effect at the level of trials. For the primary analysis, a random walk of first order was used to account for multiple follow-up outcome data within a trial. Preparations that used different total daily dose were considered separately in the analysis. To assess a potential dose-response relation, we used preparation-specific covariates assuming linearity on log relative dose.

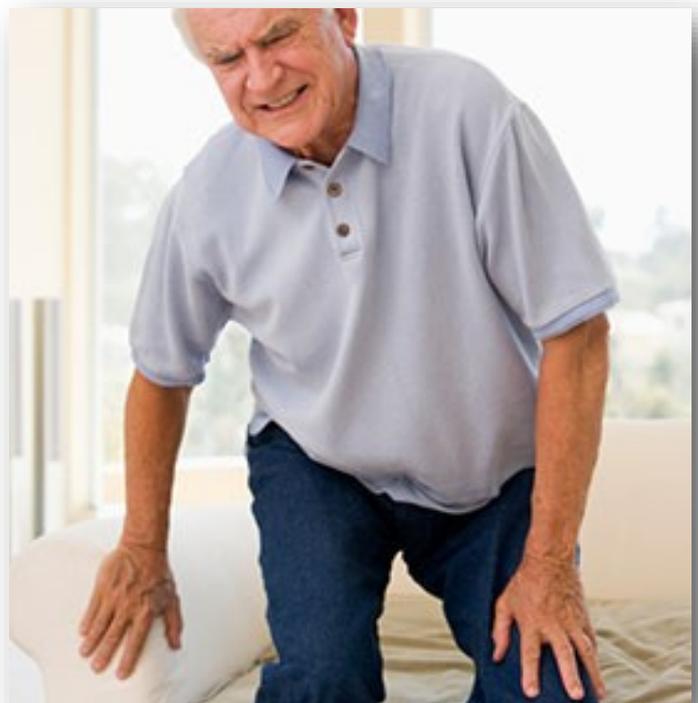
Findings

We identified 8973 manuscripts from our search, of which 74 randomised trials with a total of 58 556 patients were included in this analysis. 23 nodes concerning seven different NSAIDs or paracetamol with specific daily dose of administration or placebo were considered. All preparations, irrespective of dose, improved point estimates of pain symptoms when compared with placebo. For six interventions (diclofenac 150 mg/day, etoricoxib 30 mg/day, 60 mg/day, and 90 mg/day, and rofecoxib 25 mg/day and 50 mg/day), the probability that the difference to placebo is at or below a

prespecified minimum clinically important effect for pain reduction (effect size [ES] -0.37) was at least 95%. Among maximally approved daily doses, diclofenac 150 mg/day (ES -0.57 , 95% credibility interval [CrI] -0.69 to -0.46) and etoricoxib 60 mg/day (ES -0.58 , -0.73 to -0.43) had the highest probability to be the best intervention, both with 100% probability to reach the minimum clinically important difference. Treatment effects increased as drug dose increased, but corresponding tests for a linear dose effect were significant only for celecoxib ($p=0.030$), diclofenac ($p=0.031$), and naproxen ($p=0.026$). We found no evidence that treatment effects varied over the duration of treatment. Model fit was good, and between-trial heterogeneity and inconsistency were low in all analyses. All trials were deemed to have a low risk of bias for blinding of patients. Effect estimates did not change in sensitivity analyses with two additional statistical models and accounting for methodological quality criteria in meta-regression analysis.

Interpretation

On the basis of the available data, we see no role for single-agent paracetamol for the treatment of patients with osteoarthritis irrespective of dose. We provide sound evidence that diclofenac 150 mg/day is the most effective NSAID available at present, in terms of improving both pain and function. Nevertheless, in view of the safety profile of these drugs, physicians need to consider our results together with all known safety information when selecting the preparation and dose for individual patients. ●



World Continence Week

World Continence Week (June 20 – 26) is a timely reminder that incontinence is a significant, yet very treatable condition that can be prevented, cured or better managed in most cases, often through simple lifestyle changes.

This year, in addition to asking Australians to “improve their bottom line” by adopting healthy bladder and bowel habits, the Continence Foundation of Australia aims capture a significant portion of the population that has, until now, had limited access to information and resources.

This is the one in five Australians who live with disabilities; be they physical, intellectual, social, emotional or psychological. This group is the focus of the Continence Foundation’s major project for 2016: *Finding the answers; improving access to continence information.*

At the launch of World Continence Week the Continence Foundation will deliver a number of initiatives aimed at making their resources more accessible to people with disabilities. These include Easy English fact sheets, assistive technology for accessing the Foundation’s website, and website modifications to assist people using adaptive technologies.

Continence Foundation of Australia chief executive Rowan Cockerell said the project recognised the significant barriers people with disabilities faced every day when accessing health information. *“This is something we are doing to ensure all people, regardless of their*

personal limitations, have access to our information and resources”, Ms Cockerell said.

“This project is an extension of the work we have done previously to improve accessibility for non-English-speaking people, with our fact sheets translated into 30 languages. Being as inclusive as possible extends our reach and ability to educate and inform. And our message is the same for everyone; incontinence is, in most cases, preventable and treatable”, she said.

Ms Cockerell said the key steps to maintaining good bladder and bowel health were to eat well, drink well, be as active as possible, daily pelvic floor muscle exercises and practise good toilet habits.

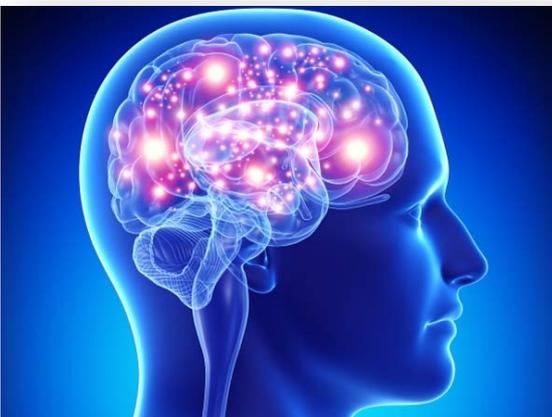
She said people shouldn’t be embarrassed about seeking help. *“There is a lot of help out there. The Continence Foundation has many resources and information on the website, as well as a free, confidential helpline staffed by continence nurses. They can provide callers with advice, information about their nearest continence service, and information about government subsidies”*, she said.

For more information about the prevention and management of incontinence go www.continence.org.au, and for free, confidential advice about incontinence, speak to one of the continence nurse advisors on the National Continence Helpline **(1800 33 00 66)** 8am to 8pm weekdays AEST. ●

Vitamin B12 May Slow Brain Ageing

By Liam Davenport

Source: Medscape - 11 May 2016



Individuals with increased levels of circulating homocysteine have faster rates of brain changes associated with aging than other people, whereas higher levels of vitamin B12 are associated with slower rates of brain aging, new research suggests.

Babak Hooshmand, MD, PhD, Center for Alzheimer Research –Aging Research Center, Karolinska Institutet, Stockholm, Sweden, and colleagues found that total brain volume losses were lower in individuals with higher baseline vitamin B12 levels, whereas the opposite was true of those with increased homocysteine levels.

“Vitamin B12 and tHcy [total homocysteine] might be independent predictors of markers of brain aging in elderly individuals without dementia”, the investigators write.

They add, *“[I]f the association is causal, supplementation with B vitamins may be effective for prevention of brain damage due to increased levels of total homocysteine. Adequately timed and powered randomized clinical trials are needed to determine efficient treatment guidelines”*.

The research was [published online](#) April 27 in *JAMA Psychiatry*. ●

New Tack On Polio Vaccine

New tack on polio vaccine on the path to eradication

Words by [Julie Milland](#)

Source: www.thecitizen.org.au
—16 April 2016

Vaccination has led to a worldwide plunge in polio infections, but cases are still occurring in poorer countries.

Global health authorities are set to take a major step in the push to eradicate polio when 145 countries start switching to a new vaccine from Sunday.

The move is designed to eliminate the possibility of infection caused by one of the types of poliovirus found in the oral polio vaccine.

Australia has not used the oral vaccine since 2005, but it is still used in developing countries because it is cheaper and easier to distribute.

Bruce Thorley, head of the WHO Polio Regional Reference Laboratory at the Doherty Institute in Melbourne, said that although the oral vaccine could cause cases of polio in rare circumstances, it was important for global eradication because it was cheaper, enabled wide coverage and did not require trained medical staff to inject the vaccine.

Polio can cause paralysis or other effects lasting decades after infection, and can be fatal. Infection occurs with one of three types of naturally occurring – or wild – poliovirus (types 1, 2 and 3) or after exposure to special weakened forms of the three types of virus in the oral vaccine.

In 2015, the World Health Organization declared wild type 2 poliovirus eradicated, but a small number of infections are still caused by the weakened type 2 virus in the oral polio vaccine or OPV, according to Dr Thorley.

"The [oral polio vaccine], in rare circumstances, can cause polio, and it's considered this occurs in about one in every 2.7 million first doses of the oral vaccine, and that's because it contains a live virus".

He said the 12 cases of vaccine-derived type 2 polio in 2015 were in countries with low vaccination rates – Guinea, Myanmar, Nigeria and Pakistan.

Although Australia no longer used the oral vaccine, Dr Thorley said people should continue to maintain scheduled vaccinations with the injectable inactivated poliomyelitis vaccine (IPV), which protects against all three types of poliovirus.

Polio in Australia

- 400,000 cases
- 40,000 cases with paralysis
- 2000 deaths
- 1950s – Polio vaccine introduced
- Early 1970s – Last case of infection in Australia
- 2000 – Australia certified polio-free
- 2005 – Oral vaccine replaced by injected inactivated polio vaccine
- 2007 – Last case of imported polio
- 2009 – June Middleton dies after 60 years in an iron lung

Source: WHO, Polio Australia, Dr Thorley

Dr Thorley said WHO declared Australia polio-free in 2000, but Australians were still at risk from people infected overseas.

"Since the 1970s, we've had single cases [of polio brought from another country] and the most recent reported imported case was in 2007".

The WHO-coordinated global "switch" in vaccine use will take place over the two weeks to May 1.

Dr Thorley said countries would switch from using oral vaccines containing types 1, 2 and 3 poliovirus (known as trivalent OPV) to an oral vaccine containing only types 1 and 3 (bivalent OPV). Countries currently using OPV would destroy any remaining stocks of trivalent OPV.

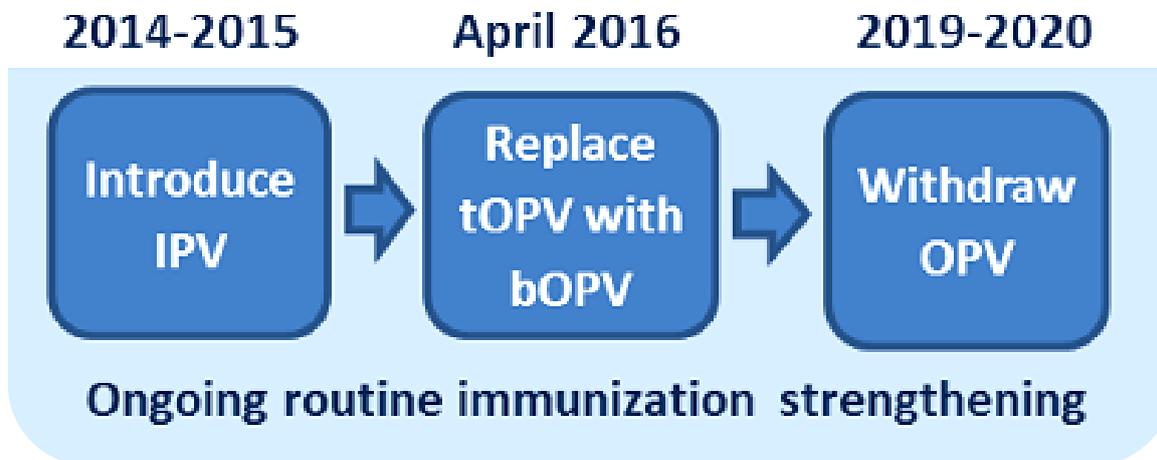
"This is a significant step because the WHO has had to negotiate with vaccine manufacturers so they can start producing enough bivalent OPV and also produce enough IPV . . . All countries will administer one dose of IPV by the time we have the switch so people will be protected against type 2".

The WHO polio vaccination program has led to a dramatic fall in polio cases from 350,000 in 1988 to just 74 in 2015, all caused by wild type 1 poliovirus in Pakistan and Afghanistan.

Wild poliovirus attacks the nerves and causes paralysis within hours in one-in-100 people infected. There is no cure for the disease, known as poliomyelitis, and only immunisation against all three types of poliovirus offers full protection.

Gillian Thomas, vice-president of Polio Australia, said poliovirus circulating in Australia (endemic) is thought to have infected approximately 400,000 people between the 1920s and the early 1970s, with about 40,000 people paralysed.

New Tack On Polio Vaccine (cont'd from P18)



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She said people with few early symptoms could nevertheless suffer "late effects of polio" decades later. Symptoms can include fatigue, muscle weakness and pain, joint pain, breathing difficulties and nerve problems.

She said Australia introduced vaccines in the 1950s and so most of the people suffering the late effects of polio tended to be older Australians.

Ms Thomas, 66, contracted paralytic polio in 1950 at 10 months of age. Although she was eventually able to walk using two full-length calipers, the late effects of polio had severely restricted her movement.

"Polio affects both my legs and one arm," she

said. "I thought my right arm got away without damage but with the late effects, it's obvious that it has been affected. So, basically, it's attacked all my limbs; so I use a wheelchair now".

Ms Thomas said the 400,000 people infected would suffer late effects of polio, making this the largest group of people with a disability in Australia. Polio Australia had set up the Australian Polio Register and is holding a conference in September to help raise awareness.

People more than 65 years of age did not have support through the National Disability Insurance Scheme and needed to rely on lesser levels of financial assistance through aged care programs. 🌟

Immunisation-Immunity For Community

Source: Department of Health & Human Services, Victoria, Australia

Immunisation prevents many illnesses in children and adults. Immunising yourself or your children is important for not only your health, but also for the health of your community because when enough people are immunised diseases no longer spread. If you want to know more about immunisation – how it works, what vaccinations you need and what the possible side effects are – speak with your GP.

Click on the image (right) to view Dr Margaret Cooper's polio story.

You can also find out more about immunisation on this website.

www.betterhealth.vic.gov.au/immunisation 🌟

Dr Margaret's Story (video)

Immunisation



Polio Vaccine 'Switch' Not Without Risks

By Helen Branswell

Source: [The Boston Globe](#) – 19th April 2016

The world is in the process of trying something it has never attempted. Over the next two weeks, 155 countries must stop using a vaccine that has been protecting children from paralyzing polioviruses for more than a half-century.

Designed in the 1950s, the vaccine has helped take the world to the edge of polio eradication. In the 1980s, polioviruses crippled 350,000 children annually; this year they have maimed 10 in the only two countries where polioviruses still spread, Pakistan and Afghanistan.

It has been a monumental achievement in public health.

But for a while now, a component of the vaccine has caused more problems than it has solved, and has resulted in a relatively small number of cases of paralysis. So between this past Sunday and May 1, all countries that use the oral polio vaccine developed more than 60 years ago must stop administering the formula and replace it with a new version.

The unprecedented synchronized campaign, more than 18 months in the planning, is appropriately known as "the switch".

Hundreds of thousands of health workers around the globe have been involved. Countries have had to develop implementation plans, train volunteers, and manage vast inventories of vaccines, including by ensuring that stocks of the old one are discarded.

"I've been working in immunization since 1974 and nothing like this has ever happened before", said Dr Walter Orenstein, a polio expert at Emory University in Georgia.

If the planners' assumptions are correct and the switch is executed as intended, the world's children will be safer.

The switch does not come without risks. There are three strains of polioviruses. The new vaccine will not have a component that protects against Type 2. For the most part, that is not a problem — Type 2 polioviruses haven't been seen since 1999 and have been declared eradicated.

But after the switch, infants in some parts of the world won't have any protection against Type 2 polio. The old vaccine includes live-but-weakened polioviruses; if there are any Type 2 vaccine viruses left in the environment — or unleashed by the unauthorized or unwitting use of stocks of the old vaccine — those children could become infected and crippled.

Mathematical modeling suggests there probably will be at least one outbreak caused by Type 2 vaccine viruses after the switch, Dr Stephen Cochi, a polio expert at the Centers for Disease Control and Prevention, told reporters last week. The Global Polio Eradication Initiative, a public-private partnership that includes the CDC and the World Health Organization, has prepared for that possibility, stockpiling vaccines that could be used to control an outbreak if the need arises.

A little background on polio and the vaccines that protect against it is useful to understand what is at work here.

Back in 1988, the WHO, CDC, UNICEF, and the service club Rotary International embarked on an ambitious plan to get rid of polio. (The Bill and Melinda Gates Foundation joined the polio eradication partnership in the last decade.) At the time, there were three strains of the virus circulating.

Since then, Type 2 polioviruses have been declared eradicated. Type 3 viruses haven't been spotted in more than three years and are also thought to be gone.

The eradication toolbox contained — then and now — only two tools: an injectable vaccine, which is made with killed viruses, and the oral vaccine, developed by Albert Sabin.

Each has strengths and weaknesses. The injectable vaccine, which is used in the United States and most affluent countries, is safer; it does not paralyze. But it is more expensive and because it is injected, it must be administered by a health professional. The oral vaccine costs pennies a dose, and anyone with a few minutes of training can squeeze the drops into a child's open mouth.

Children who get the oral vaccine excrete those live-but-weakened vaccine viruses for a time when they have bowel movements. In places where sanitation is rudimentary, that initially was beneficial. Vaccinate some kids in a community and others will eventually also be protected as the vaccine viruses spread.

But as vaccine viruses move from one child's gut to the next, they evolve and can regain the ability to paralyze. When polio was crippling hundreds of thousands of children a year, the oral vaccine's advantages far exceeded its negatives. But as the polio math has shifted, so too have the scales on which the vaccine's risks and benefits are weighed.

Last year there were 74 children in the world paralyzed by polio. But 37 children were paralyzed by vaccine-derived polioviruses.

Takeda To Produce Cheap Polio Vaccine

With a polio-free world within reach, the Bill & Melinda Gates Foundation is funding a Japanese company to produce a low-cost vaccine.

Source: www.sbs.com.au/ AAP – 9 May 2016

Japan's Takeda Pharmaceuticals is to get \$US38 million (\$A51.65 million) from the Bill & Melinda Gates Foundation to develop a crucial, low-cost polio vaccine for use in developing countries.

As part of a global plan to eradicate the crippling disease, with experts saying the world could see the last case this year, countries will need to switch from using oral polio vaccine (OPV) to using so-called inactivated polio vaccine (IPV) to ensure the disease does not reappear.

Experts fear a substantial worldwide shortage of IPV once every country in the world is ready to make the switch, and polio eradication strategists have been looking at how to avert that shortfall by encouraging new manufacturers into the sector.

Chris Elias, the Gates Foundation's head of global development, said the partnership would help "ensure that the world has enough vaccine to get the job done and maintain a polio-free world".

Takeda said in a statement it would use the Gates funding to develop, licence and supply at least 50 million doses per year of so-called Sabin-strain inactivated poliovirus vaccine (sIPV) to

more than 70 developing countries.

The shot will be made available at an affordable price for countries supported by the GAVI vaccines alliance, which is backed by the Gates Foundation, the World Health Organisation, UNICEF and others to fund immunisation programs in poor countries.

Polio invades the nervous system and can cause irreversible paralysis within hours - and WHO's repeated warning is that as long as any polio virus is circulating, people are at risk.

But the world is now on the brink of wiping out polio forever, with only 12 cases of the contagious viral disease recorded worldwide so far this year - in Pakistan and Afghanistan.

Global health experts say stopping all polio transmission is possible by the end of this year. The full official, global eradication of polio could be declared by the end of this decade.

Rajeev Venkayya, head of vaccines for Takeda, said the Gates funding would enable his firm to de-risk the investment needed to take the sIPV through final stage clinical trials, licensure, and then onto the market.

The vaccine, which was originally licensed from the Japan Polio Research Institute, has already completed mid-stage Phase II trials, Venkayya said. Once it has been fully developed, tested and licensed, it will be manufactured at Takeda's facility in Hikari, Japan. ●

The 'Miracle' Glioblastoma Drug

What '60 Minutes' Still Isn't Saying About The 'Miracle' Glioblastoma Drug

By [Arlene Weintraub](#), Contributor
I cover the science and business behind drug development and health.

Source: Forbes.com – 16 May 2016
Opinions expressed by Forbes Contributors are their own.

Last night, the hit CBS news program *60 Minutes* revisited a trial at Duke University that it had devoted two segments to early last year. Scientists at Duke are testing a modified form of the polio virus to treat glioblastoma, and the reason for the *60 Minutes* update was that the research has recently been granted "breakthrough" status by the FDA—which may shave some time off the development pathway. The development of engineered viruses, or "oncolytic viruses", to treat cancer is one type of immunotherapy that's generating excitement in oncology circles.

The breakthrough status for Duke is good news, to be sure. Median survival for patients with glioblastoma who are treated with traditional chemotherapy is only about 14 months and two-year survival is 30%, according to the American Brain Tumor Association. The disease claims 12,000 people per year in the U.S. and was to blame for the death of Vice President Joe Biden's son. Biden is now leading the government's cancer "moonshot" initiative, and as part of that he visited Duke, where he met the first patient treated with the virus, Stephanie Lipscomb, who entered the trial in 2012 and is still cancer-free.

But winning breakthrough status from the FDA doesn't guarantee that any treatment is actually a breakthrough. The Duke team has plenty of hurdles to overcome before the modified virus can become an approved treatment. In fact, the *60 Minutes* segment revealed that one of the patients hailed as a miracle in last year's broadcast, Nancy Justice, suffered a recurrence of her brain tumor and died on April 6 at age 60.

The 'Miracle' Glioblastoma Drug (cont'd from P22)

And it's important to remember that Justice, Lipscomb and the other 19 patients treated so far were in a Phase I trial in which 8 patients have died, three have achieved long-term remissions and the rest are still being monitored. That means it's too early to judge how the virus will perform in a larger patient population.

Here are some other key points to keep in mind about Duke's cancer-fighting polio virus.

Polio is not the only virus that's been shown to work against cancer. Several companies and academic groups are testing a variety of engineered viruses to fight cancer, including herpes, vaccinia (cowpox) and adenovirus. And in October, the first virus-based drug was approved by the FDA, Amgen AMGN +0.56%'s Imlygic (talimogene laherparepvec, or T-VEC) for the treatment of melanoma. It's an engineered form of the herpes virus that's injected straight into melanoma tumors, where it kills cancer cells directly and also recruits immune-boosting cells to the tumors to boost its potency. It's far from a miracle—studies show that it works best in a small subset of patients who are in Stage III of the disease, but overall it improves survival by only a few months—which is likely why the FDA declined to fast-track the drug to market last year.

But Amgen is still investigating Imlygic in different settings, which brings us to our next point...

Engineered viruses may work better in combo treatments than they do alone. The *60 Minutes* update introduced viewers to Brendan Steele, another participant in the Duke trials who went into remission after being treated with the modified polio virus. Seven months later, his cancer returned, so his doctors gave him a dose of chemotherapy. Oddly, his brain tumor melted away after that, even though he had not

responded well to chemotherapy prior to receiving the virus.

Steele's reaction led Duke's researchers to surmise that the immune response prompted by the virus may actually boost the effectiveness of chemotherapy. This idea is gaining steam among researchers and there are now trials underway combining oncolytic viruses with other treatments.

In the case of Imlygic, it is currently in a late-stage clinical trial in melanoma in combination with another type of immunotherapy, Merck's Keytruda (pembrolizumab), which inhibits the immune "checkpoint" PD-1. In an early trial, 56% of patients responded well to the treatment and two went into complete remissions—better results than had previously been seen with either drug alone.

Just because polio kills tumor cells in the test tube doesn't mean it works in people.

Towards the end of the two-segment *60 Minutes* feature, correspondent Scott Pelley told viewers that "in the laboratory" the engineered polio virus killed cancers of the skin, lung, stomach and more. He then had one of the researchers show how it caused a breast tumor from a mouse to shrink. Seeing as the polio virus has not even moved into late-stage testing in people with glioblastoma, it seems premature to start declaring the treatment to be a cure-all for so many cancers based on some experiments in test tubes and mice.

Even one of Duke's scientists urged caution. Darell Bigner, director of the Preston Robert Tisch Brain Tumor Center at Duke, told Pelley he's optimistic that years of science may finally be coming together for glioblastoma patients, a sentiment he called "enormous". But, he added, "I have to be very careful. I never want to give anyone false hope".

[Click to watch](#)



Polio This Week

Source: [Polio Global Eradication Initiative](#) — as of Wednesday 1 June 2016

From 17 April to 1 May, 155 countries and territories participated in the historic trivalent to bivalent oral polio vaccine switch, withdrawing the type two component of the vaccine to protect future generations against circulating vaccine-derived polioviruses. Track the switch live.

Wild Poliovirus Type 1 and Circulating Vaccine-Derived Poliovirus Cases

Total cases	Year-to-date 2016		Year-to-date 2015		Total in 2015	
	WPV	cVDPV	WPV	cVDPV	WPV	cVDPV
Globally	16	3	26	2	74	32
- in endemic countries	16	0	26	2	74	3
- in non-endemic countries	0	3	0	0	0	29

Case Breakdown by Country

Countries	Year-to-date 2016		Year-to-date 2015		Total in 2015		Onset of paralysis of most recent case	
	WPV	cVDPV	WPV	cVDPV	WPV	cVDPV	WPV	cVDPV
Afghanistan	5	0	2	0	20	0	04-Apr-16	NA
Pakistan	11	0	24	2	54	2	26-Apr-16	09-Feb-15
Guinea	0	0	0	0	0	7	NA	14-Dec-15
Lao PDR	0	3	0	0	0	8	NA	11-Jan-16
Madagascar	0	0	0	0	0	10	NA	22-Aug-15
Myanmar	0	0	0	0	0	2	NA	05-Oct-15
Nigeria	0	0	0	0	0	1	NA	16-May-15
Ukraine	0	0	0	0	0	2	NA	07-Jul-15

NA: onset of paralysis in most recent case is prior to 2015. Figures exclude non-AFP sources. Madagascar, Ukraine and Lao PDR cVDPV1, all others cVDPV2. cVDPV definition: see document "Reporting and classification of vaccine-derived polioviruses" at www.polioeradication.org/Portals/0/Document/Resources/VDPV_ReportingClassification.pdf. Implementation as of 15 August 2015. ●

