



# Polio Australia Incorporated

Representing polio survivors throughout Australia



## e-Bulletin April Reflections 2012

This year's first quarter has been a whirlwind of activities for Polio Australia. During March, Canadian polio survivor, [Ramesh Ferris](#), visited [Melbourne](#) for a series of [presentations](#) which were jointly coordinated by [Polio Australia](#) and [Post Polio Victoria](#), and funded by [GlaxoSmithKline](#). One week later, Polio Australia was at the table for the House of Representatives Standing Committee on Health and Ageing [Roundtable Forum](#) into services for polio survivors in Australia. Then the 3rd [Polio Health and Wellness Retreat](#) was held on the Sunshine Coast in Queensland! More details on these activities will be in the next edition of "Polio Oz News".

In the meantime, we learned that two major funding submissions we had in with the Department of Health and Ageing were unsuccessful, which leaves Polio Australia as unfunded by the government in 2012 as it was when it was incorporated in 2008. Although I have only worked with the polio community since 2004, I have heard at least one new voice lamenting the lack of services for polio survivors every day (including weekends!) for the past 8 years. So, to do the math, that's 335 people over 335 days (less 4 weeks holiday) multiplied by 8 years = 2,680 people seeking polio-specific support. And that's just the people I've spoken to! Isn't it time polio survivors were heard by the policy makers? We know there are tens of thousands of people in Australia living with the late effects of polio and we look forward to being joined by some of you on [Wednesday 31st October](#) when polio hits Canberra for its "We're Still Here!" campaign!  
- *Mary-ann Liethof, Editor*

*Your present circumstances don't determine where you can go; they merely determine where you start.*  
~ Nido Qubein

### ***In this e-Bulletin***

- ◆ [YourHealthNet Website Launched](#)
- ◆ [Guideline: IVIg](#)
- ◆ [Engaging the Disability Sector in the NDIS](#)
- ◆ [More Choice for Older Australians](#)
- ◆ [Therapy Services to Help Older Australians](#)
- ◆ [Jetstar Out of Pocket](#)
- ◆ [National Library of Australia: Picture Australia](#)
- ◆ [Polio This Week](#)
- ◆ [Rotarians Celebrate Milestones](#)

### ***YourHealthNet Website Launched***

Source: "***Health Knowledge Network Resource Bulletin***" – April 2012



More than ever before people want to be actively engaged in decision making about their health and treatments for themselves and family members. In order to make evidence-informed decisions we need to have access to research which is of high quality and from independent sources. Systematic reviews provide an invaluable source of the latest research evidence on which to base decisions.

However, the evidence in systematic reviews is not always easy for consumers to access or understand. That's why the Centre for Health Communication and Participation has just launched its new consumer website, *YourHealthNet* – *navigating effective treatments with systematic reviews* (<http://navigatingeffectivetreatments.org.au>).

*YourHealthNet* explains evidence-based health research and systematic reviews in a visually appealing and user-friendly way. The diagrams we've developed to explain the concept, contents and process of publishing a Cochrane systematic review are particularly unique and we hope they will be useful tools for anyone interested or involved in Cochrane. The site also provides audio recordings of real world consumer stories, where individuals describe how they used Cochrane reviews to inform their health decision making. On the "Resources" page we include a series of useful links to other consumer-oriented health research websites.

**Editor's Note:** *there has only been one Cochrane review done on Post Polio Syndrome which can be viewed [here](#).*

## Guideline: IVIg Effective for Certain Nerve and Muscle Disorders

Source: [American Academy of Neurology \(AAN\)](#) – 20/3/2012

Newswise — ST. PAUL, Minn. – Intravenous immune globulin (IVIg) is an effective treatment for certain disorders of the nerve and muscles, including Guillain-Barré syndrome (GBS) and a form of neuropathy called chronic inflammatory demyelinating polyneuropathy (CIDP), according to a guideline issued by the American Academy of Neurology. The guideline is published in the March 27, 2012, print issue of *Neurology*®, the medical journal of the American Academy of Neurology.

IVIg is a type of immunotherapy that fights the misdirected immune system. It is not well understood exactly how IVIg works, but it likely regulates an overactive immune system. Immune globulin is a protein in human blood that likely links itself with antibodies or other substances directed at the nerve.

According to the guideline, strong evidence shows that IVIg effectively treats Guillain-Barré syndrome, a rare disorder in which the body's immune system attacks the peripheral nervous system, causing tingling and weakness in the arms and legs. The evidence shows that IVIg works as well as the treatment called plasma exchange to treat GBS.

Strong evidence also shows that long-term use of IVIg can help treat CIDP, which is the chronic counterpart of GBS and can affect nerves in the arms and legs and other parts of the body.

“Serious side effects are rare with IVIg, but there is a risk of kidney failure and a condition that causes the blood to be more likely to form clots,” said guideline lead author Huneed S. Patwa, MD, of Yale University and the VA Connecticut Healthcare System in West Haven and a member of the American Academy of Neurology. “It is important to work with your doctor when deciding whether to use IVIg for a neuromuscular disorder.”

The guideline also found that IVIg is effective in helping to treat moderate to severe forms of myasthenia gravis and a rare condition known as multifocal motor neuropathy. It may also be helpful in treating neuromuscular disorders known as nonresponsive dermatomyositis and Lambert-Eaton myasthenic syndrome.

Learn more about this latest guideline and nerve and muscle disorders at <http://www.aan.com/patients>.

**Editor's Note:** *the results of a study into the use of IVIg for Post Polio Syndrome was published in [2006](#), and clinical trials are continuing under the direction of [Dr Kristian Borg](#) at the Karolinska Institute in Sweden.*

## STOP PRESS!!!

### Federal Budget 2012-13

Source: [National Disability Insurance Scheme](#) website – May 2012

The Australian Government has committed \$1 billion to support the first stage of a National Disability Insurance Scheme (NDIS).

The funding will see an NDIS start in mid-2013 for around 10,000 people with significant and permanent disabilities in select locations across the country. This will increase to 20,000 people from mid-2014. The funding in the Budget includes the establishment of a new National Disability Transition Agency to run the delivery of care and support to people with disability, their families and carers in the select locations.

The initial locations will be worked out with the states and territories – who have all agreed their shared responsibility for the fundamental reform of disability care and support.

People with disability, their families and carers as well as support workers, service providers and advocates will play an important part in informing the design of the first stage of an NDIS.

This announcement is an important step towards making an NDIS real for people with disability, their families and carers, and to giving all Australians the peace of mind that if something happens to them or to a loved one, there will be a helping hand when they need it.

For more information:

- [Budget media release](#)
- [Delivering a Stronger, Fairer Future](#)

For all information about NDIS, please go to: [www.ndis.gov.au](http://www.ndis.gov.au)



## More Choice, Easier Access and Better Care for Older Australians

Source: **Joint Media Release** - 20 April 2012

The Hon Julia Gillard MP, Prime Minister of Australia

The Hon Mark Butler MP, Minister for Social Inclusion, Minister for Mental Health and Ageing

Under landmark changes to the aged care system, more people will get to keep their home, and more people will get to stay in their home as they receive aged care.

Prime Minister Julia Gillard and the Minister for Ageing, Mark Butler, today announced a 10-year plan to reshape aged care, beginning 1 July 2012.

The Gillard Labor Government will deliver the \$3.7 billion *Living Longer Living Better* plan to deliver more choice, easier access and better care for older Australians and their families.

For the first time, we will also introduce fairness into the payment system. Right now, pensioners often pay more than people with hundreds of thousands of dollars in assets and a private income. As a result, pensioners are subsidising the accommodation and care costs of millionaires.

From now on the system will be fairer, based on capacity to pay. The amount you pay for aged care services will be capped and underpinned by tightened means testing, meaning older Australians will not be forced into a fire sale of the family home in order to get access to aged care.

This package reflects in large part what older Australians, their families and carers, and aged care providers have told is wrong with the system, along with the valuable input of the Productivity Commission report, *Caring for Older Australians*.

Implementation of the reforms will be overseen by a new Aged Care Reform Implementation Council. The new reform package will be implemented in stages to enable providers and consumers to gain early benefits of key changes and have time to adapt and plan for further reform over the 10 years.

Read the full Media Release [here](#).



## Therapy Services to Help Older Australians to Age Well

Source: [Media Release](#) - 11 April 2012

The Hon Mark Butler MP, Minister for Social Inclusion, Minister for Mental Health and Ageing



More than 70,000 older Australians will continue to receive subsidised physiotherapy, occupational therapy, speech therapy and podiatry services for the next 3 years.

Minister for Mental Health and Ageing Mark Butler announced today that funding for the Day Therapy Centre (DTC) program would be extended until 30 June 2015.

The Gillard Labor Government is providing more funding, for more services, to more older Australians than ever before. The Government will provide more than \$38 million each year to more than 140 day therapy centres across Australia, allowing them to provide a wide variety of therapies which can help older Australians to either maintain or recover their independence.

“Older Australians are living longer, healthier and more prosperous lives than ever before and the overwhelming message that I’m hearing is that they want more support to live independently for as long as possible,” Mr Butler said. “Our continued support of day therapy services will support our ageing population to age well and remain in their own

homes and communities, close to family and friends.”

During 2010-11, nearly 74,000 people were assisted under the program and more than 800,000 hours of therapy were provided. Giving older Australians more choice in the support and care they receive and support to remain in their own homes is critical to the efforts to build a sustainable aged care system that meets the needs of older Australians and their families.

## Jetstar Out of Pocket Even if it Wins Wheelchair Appeal

by Leonie Lamont

Source: [smh.com.au](http://smh.com.au) (The Sydney Morning Herald) - April 26, 2012

JETSTAR may well be pondering how many extra wheelchairs it could have provided for disabled passengers, as it weighs the dollar cost of what constitutes "public interest" in a disability discrimination stoush in the Federal Court.

Jetstar and Virgin Australia have been accused of discrimination by Sheila King, 78, who is reliant on a wheelchair as a result of post-polio syndrome, and a car crash in 2008. At stake is the business model of the low-cost airlines, which restrict wheelchair-assisted passengers to two per flight.

It was Jetstar's tight margins as a low-cost operator that convinced Federal Court judge Justice Alan Robertson that although Mrs King had been discriminated against, Jetstar was allowed to do so because of "unjustifiable hardship" provisions. Mrs King has appealed.

It was the question of litigating in the "public interest" that swayed the court this week to agree to a protective costs order that will see Jetstar out of pocket, even if Mrs King loses. Justice Nye Perram agreed to Mrs King's request to cap costs at \$10,000, saying the public interest proposition being put was that "low-cost operators ought not be achieving their margins at the expense of disabled persons". Mrs King is being represented pro bono and with some legal aid funding.

The judge was sympathetic to Jetstar's position - and that at the initial trial costs were capped at \$20,000. Jetstar has estimated its appeal costs lie between \$100,000-\$180,000. No date has been set for the appeal or the Virgin Australia trial.

Read full article [here](#).



## National Library of Australia: Picture Australia



*Picture Australia could be of interest to anyone who has old 'polio' photos they would like to be kept for posterity! If that sounds like you, read on . .*

*- Ed*

[Picture Australia](#) is an Internet based service that allows you to search many significant online pictorial collections at the same time. When you do a search on Picture Australia, thumbnail images are retrieved from [participating institutions](#) on the fly and inserted into the search results.

Picture Australia provides access to images that cover all aspects of Australiana:

- Artworks include paintings, drawings, prints and posters of abstract art, fine art and portraits
- Photographs capture people, places and events
- Objects include sculpture, scrimshaw, bark, costume, weapons
- Images may be in black and white or full colour.

The benefits of contributing as an individual enable you to:

- [play your part](#) in telling the full story: contribute your [Flickr](#) images to the groups and help enrich Picture Australia's collection;
- help democratise history and establish a collective memory of places and events around the country;
- possibly be collected for perpetuity by a collecting institution. Picture curators across the country are sent regular reports on the latest images coming into Flickr groups;
- using the 'request a copy' service Picture Australia users can contact Flickr photographers directly to purchase copies of your images.

## Polio this week

Source: [Polio Global Eradication Initiative](#) - as of Wednesday 2 May 2012

Total cases	Year-to-date 2012	Year-to-date 2011	Total in 2011*
Globally	52	123	650
- in endemic countries	49	43	341
- in non-endemic countries	3	77	309

Countries	Year-to-date 2012				Year-to-date 2011				Total in 2011	Date of most recent case
	WPV1	WPV3	W1W3	Total	WPV1	WPV3	W1W3	Total		
Nigeria	21	7		28	6	2		8	62	26-Mar-12
Afghanistan	6			6	1			1	80	14-Mar-12
Pakistan	13	1	1	15	33			33	198	11-Mar-12
India					1			1	1	13-Jan-11
Chad	3			3	23	2		25	132	21-Feb-12
DR Congo					46			46	93	20-Dec-11
Angola					2			2	5	07-Jul-11
Niger						1		1	5	22-Dec-11
CAR									4	08-Dec-11
China									21	09-Oct-11
Guinea									3	03-Aug-11
Kenya									1	30-Jul-11
Côte d'Ivoire						3		3	36	24-Jul-11
Mali						1		1	7	23-Jun-11
Congo					1			1	1	22-Jan-11
Gabon					1			1	1	15-Jan-11
<b>Total</b>	<b>43</b>	<b>8</b>	<b>1</b>	<b>52</b>	<b>111</b>	<b>9</b>	<b>0</b>	<b>123</b>	<b>650</b>	
<b>Total in endemic countries</b>	<b>40</b>	<b>8</b>	<b>1</b>	<b>49</b>	<b>41</b>	<b>2</b>	<b>0</b>	<b>43</b>	<b>341</b>	
<b>Total outbreak</b>	<b>3</b>	<b>0</b>	<b>0</b>	<b>3</b>	<b>73</b>	<b>7</b>	<b>0</b>	<b>80</b>	<b>309</b>	

Data in WHO as of 03 May 2011 for 2011 data and 01 May 2012 for 2012 data.

## Rotarians Celebrate Milestones in the Fight to Rid the World of Polio

by Ryan Hyland

Source: [Rotary International News](#) – 8 May 2012

Rotarians Tuesday celebrated two major milestones in the organization's decades-long fight to rid the world of polio with a laser light show at the 2012 RI Convention in Bangkok, Thailand.

During the third plenary session, which was also made available through a live webcast, Rotarians were congratulated for meeting and exceeding Rotary's US\$200 Million Challenge, Rotary's response to \$355 million in matching grants from the Bill & Melinda Gates Foundation for polio eradication efforts. Attendees also celebrated India's removal from the polio-endemic list in February, which leaves only three countries where transmission of the virus has never been stopped.

But speakers reminded the festive assembly that the work is far from complete, because the ultimate goal has not been reached. "We know that we haven't reached our goal. We haven't ended polio," said John F. Germ, chair of Rotary's US\$200 Million Challenge Committee. "Our clubs are still planning polio fundraisers for the coming years and encouraging donations from people in their communities."

Germ announced that, as of 4 May, Rotarians and supporters have raised \$215.7 million for the challenge, which runs through June. But with the Global Polio Eradication Initiative facing a significant funding shortfall for 2012 and beyond, it is vital for clubs and districts to keep pushing forward with their many creative fundraisers. ([Download Germ's speech](#) or watch a [video of the third plenary](#))