



Polio Australia Incorporated

Representing polio survivors throughout Australia



e-Bulletin June Reflections 2011

We have reached that time of year when those of us in the southern hemisphere are braving the winter chills whilst our northern neighbours are enjoying the sun. Fortunately for we Australians, we live in such a vast continent that we can always find *somewhere* warm without ever leaving the country. However, as not being able to regulate body temperature can be a symptom of the late effects of polio, many polio survivors will be working extra hard to keep warm (or cool), which all adds to those monthly bills! Check Page 3 for tips on how to survive July.

*"If we had no winter, the spring would not be so pleasant:
if we did not sometimes taste of adversity, prosperity would not be so welcome."*
- Anne Bradstreet

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Stay out of Australia's Medicines

24 June 2011

Consumers Health Forum (CHF), alongside sixty of Australia's biggest health consumer organisations, has backed a new campaign which condemns the Federal Government for purposely shelving critical drugs needed by chronically ill Australians so that the Government can keep the budget in surplus. To notify consumers of the Government's interference in their access to medicines, CHF released a [statement of intent](#). To read the CHF media release click [here](#).

As the consumer campaign was launched on 21 June 2011, Health Minister Nicola Roxon announced the listing of 13 new drugs on the PBS. CHF issued a response which can be found [here](#).

Vaccine compo on agenda

by Sue Dunlevy, *The Australian*, 28th June 2011



People who suffer serious adverse reactions to vaccines may get compensation for their injuries after Health Minister Nicola Roxon agreed to take advice on the need for a no-fault compensation scheme.

The Australian revealed yesterday that two of Australia's top epidemiologists were calling for the introduction of a victim compensation scheme such as those used in 19 other nations, including the US, New Zealand and Canada and much of Europe. The call comes in the wake of cases such as that of Queensland teenager Jacob McCarthy, who has the painful and paralytic symptoms of polio after being given a vaccine intended to protect him from the debilitating illness when he was a baby.

"I'm happy to look at any advice and options that are put forward," Ms Roxon said. "It's something that's been talked about for decades. It's something that may well be able to be considered as our government works through a national disability insurance scheme, which is also being considered."

Read the full story [here](#) or more about the idea of a no-fault compensation scheme [here](#).

Here we go again!



Polio Australia Delegation

(L-R) Standing: Neil von Schill, Catherine King MP,
Dr John Tierney, Peter Garde
Sitting: Gillian Thomas and Mary-ann Liethof

During Polio Australia's seventh lobbying visit to Canberra, we were delighted to meet up with three of our [Parliamentary Patrons](#), Catherine King, Mark Coulton and Greg Hunt, as well as [Peter Dutton](#), [Jan McLucas](#), [Karen Andrews](#), [Mitch Fifield](#), [Claire Moore](#), and Health Minister, [Nicola Roxon](#)'s Adviser, Angela Koutoulas.

Although we are yet to receive any funding from federal Government, we are always rewarded with additional suggestions from our bi-partisan political supporters. The fact that every Minister and Senator we meet acknowledges that the Australian Government is not doing enough to support our post-polio citizens prompts us to continue striving for the financial recognition we need to enable Polio Australia to achieve its mission of "ensuring that polio survivors have access to appropriate health care and the support required to maintain independence and make informed lifestyle choices". We are certainly doing our best with only one philanthropically paid worker and untold volunteer hours by dedicated members of our Committee of Management.

An additional bonus encountered through our recent interaction with the federal Government was an invitation to participate in consultations on the Department of Health and Ageing's [New flexible funds – program consolidation](#) in the coming months. We look forward to reporting on the outcome of this in due course.

What did you have for breakfast?

In a 1998 article by Dr Lauro S. Halstead (National Rehabilitation Hospital, Washington, DC) entitled "[Nutrition and Post-Polio](#)", he talked about his personal journey to learn more about nutrition. Nothing much has changed since then, apart from the fact that we are all more than a decade older and may benefit from a review of our eating practices. Dr Halstead identifies the following facts about protein:

"First, proteins are in all human cells. In fact, they form the basic building blocks for each cell, its metabolism, and life itself.

Second, proteins are made from amino acids, and new proteins are being made (synthesized) and broken down (degraded) each day. This protein turnover applies to muscle cells, as well, which are constantly synthesizing new protein every day. Some of this new protein comes from what we eat and some comes from "re-built" protein using amino acids already in the body.

The third thing I learned, and most important for persons with post-polio syndrome, the largest "consumer" of protein in the body is muscle.

All of this means that for the muscles to have a fighting chance to maintain or increase their strength, there has to be a generous amount of protein in the diet. We are not carnivores by chance."

If you are ready to find a dietitian/nutritionist in your area, check the Dietitians Association of Australia (DAA) website [here](#). Also, talk to your GP about [Medicare rebates for allied health services](#) which are available for patients with chronic conditions and complex care needs (like the late effects of polio). This entitles you to five free visits to certain allied health professionals, including dietitians.



[Polio this week](#) as of Wednesday 28 June 2011

Source: *Polio Global Eradication Initiative*

Total cases	Year-to-date 2011	Year-to-date 2010*	Total in 2010**
Globally	241	455	1349
• in endemic countries:	79	64	232
• in non-endemic countries:	162	391	1117

Grab Bars

from PHI's [Polio Place](#) website

Grab bars are useful in many locations. For example, if a stairway has a chairlift, it is a good idea to place grab bars at both the top and bottom. Or, even if there is only a step up of a few inches at a doorway, a grab bar will help the disabled achieve the extra stability needed to enter or exit their home.

However, most of the grab bars are installed in bathrooms. Do not approach the project with set heights and widths. Rather, ask the disabled person to demonstrate how he or she maneuvers in the bathroom. Sometimes a "vertical" bar seems best, especially if the person needs to pull out of a wheelchair. Mostly we install the bars "horizontally," because balancing and assuring secure movement are the two critical objectives. We replace all towel bars with actual grab bars. ([See our method of mounting grab bars.](#)) And, most of the time, we find it best to "ring" the whole bathroom and tub or shower with grab bars. Bathrooms demand difficult maneuvers and having multiple places to hold on to can stop a needless fall. Read more [here](#).

The Universal House



The following information may be useful for anyone considering building their own house. The Universal design has been defined as the design of products and environments so that they are usable by all people, to the greatest extent possible, without the need for adaptation or specialized design. The intention being to simplify life for everyone by making more housing usable by more people at minimal extra cost.

A Universal House uses building features, fittings and products in combination to increase usability, benefiting people of all ages and abilities. For example, a doorway or passageway is more easily navigated by users of mobility devices such as walking frames, wheelchairs or even a children's pram if it is slightly wider than typical.

With regard to fittings, people with limited hand function find screw-type sink taps more difficult to use than lever-type taps which can be used by everyone. A similar benefit is found in using lever-type door handles and rocker electrical switches; incorporating the most usable fittings at the time of construction reduces the need for later retrofitting. A Universal House will ensure rooms and services within the home are of a size and type which is usable by as many people as possible. Read more [here](#).

Tips for Cold Intolerance

The British Polio Fellowship has a wonderful resource called [Cold Intolerance: Information for people with polio or post polio syndrome \(PPS\)](#). Here are a few of the "Other Tips" listed in this informative document.

There are many pieces of equipment to help you keep warm, from tiny hand-warmers that can be tucked into your gloves to electric blankets. Be cautious with these items and make sure you don't burn your skin. For example, use a specially designed cover if you use a hot water bottle and never put it straight against your skin without a cover.

Wheat bags, cloth bags full of wheat grains that are heated briefly in the microwave, are generally safer than hot water bottles as there is no need to handle hot water, worry about leakages or any cap to try to screw into place. They come in various shapes and sizes, may be draped over the body as needed and are available with soothing essential oils, such as lavender.

If you can, always warm the bed before getting in. You could use an electric blanket or a couple of wheat bags or hot water bottles.

If you are going to be sitting for a while try to put your feet up. By raising your legs you are helping your circulation, as it no longer needs to fight against gravity to get blood back from your feet to your heart. A light travel blanket draped over your lap can also make a difference.

Warm drinks are a pleasant help towards the process of keeping warm and soup can be both nourishing and comforting.



Run, Audrey, Run!

Canberra-based Audrey Clarke will be doing the [City2Surf](#) run in Sydney to raise funds for Polio Australia. As her mum is a survivor of polio, Audrey believes this is a perfect opportunity to be involved with a charity close to her heart.

Please help Audrey help others affected by polio by sponsoring her for the 14km City2Surf run in Sydney this August 14th. All donations will go directly to Polio Australia.

Donations can be made directly (internet banking or bank deposit) to Polio Australia Incorporated / Westpac / BSB 032078 / Account 000555766 – please make reference to: **'Audrey Clarke City2Surf run'**. Fun Run and general donations can also be made to Polio Australia via PayPal [here](#).



Chain of Protection

[This website](#) is home to a series of videos on immunisation including: The Chain of Protection, Herd Immunity, Whooping Cough, How Diseases Transmit, Meningococcal Disease and Disease Prevention. They were produced by Professor Robert Booy from the National Centre for Immunisation Research & Surveillance (NCIRS) at The Children's Hospital at Westmead and The University of Sydney in conjunction with Blirt Marketing and Jenny Granger (marketing consultant). Professor Robert Booy is Head of Clinical Research at NCIRS. Professor Booy is also a member of Polio Australia's [Clinical Advisory Group](#).

Wayne's Work in Cambodia – Can you help?

Victoria's Wayne Slattery will be flying to Cambodia in late July - his fourth trip in 12 months! As polio in Cambodia was only eradicated in the last 10 years, there are plenty of young polio survivors in Cambodia requiring help. Wayne is currently looking for donations of wheelchairs and/or equipment to take with him. Read more about Wayne's work and contact details [here](#).

Polio-World Photo Contest



Living with Polio



Polio-World is inviting people to send photographs showing their individual history of Polio. They are looking for three photos: the first one to show Polio, the second depicting Living with Polio and the third Adapting to Post-Polio.

Polio-World will use the photographs to create an awareness of post-polio and to show the world that WE ARE STILL HERE!

Polio

Post Polio

My name is Charlie, and I live in Tucson, Arizona USA. I got polio in 1952 and starting having Post-polio symptoms around 1985. I am a retired surgical nurse, and a current glider pilot. Although I don't perform gymnastics anymore, I still haven't let Post-Polio stop me from being active.

To participate, send your submission to: mickiminner@msn.com with a description of 50 words or less. Please put **Polio-World** in the subject line, a brief description of yourself in the e-mail (*see example left*), and attach your three photographs.

Deadline is 1 September 2011 — Be CREATIVE!

Please pass this e-Bulletin on to friends and colleagues who have an interest in the late effects of polio

- ◆ If you are not the original recipient of this e-Bulletin and would like to receive it directly in future, please email us [here](#).
- ◆ If you do not wish to receive any further communication from Polio Australia, please email us [here](#).

[Polio Australia Incorporated](#)

PO Box 500 Kew East Vic 3102

Suite 119C, 89 High Street Kew Vic 3101

Telephone: (03) 9016 7678 ◆ Mobile: 0466 718 222

E-mail: office@polioaustralia.org.au ◆ Website: www.polioaustralia.org.au