



Polio Australia Incorporated

Representing polio survivors throughout Australia



e-Bulletin July Reflections 2011

In late August 2011, Polio Australia's National Program Manager, Mary-ann Liethof, will be travelling to Copenhagen, Denmark to attend [The European Conference on Post Polio Syndrome](#) being held from 31 August until 2 September 2011. The Conference is hosted by the European Polio Union (EPU) and The Danish Society of Polio and Accident Victims (PTU). By mid-July 2011 the organisers reported that they had registered nearly 300 participants from 25 countries. Mary-ann will be blogging daily while she is away so we can all benefit from what she learns. Visit Polio Australia's website often to keep up to date with her [Daily Danish Doings](#). On her return to Australia in September, *Polio Oz News* will carry more reports from the Conference and her meetings.

I am always ready to learn although I do not always like being taught.
~ Winston Churchill

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Australian Polio Register goes 'live'!

After almost a year of toil, Polio Australia's President, Gillian Thomas, has proudly unveiled the new online [Australian Polio Register](#). You can now select to view the information by family name, maiden name, given names, year of birth, year and age contracted polio, and where polio was contracted.

If you believe you have registered but don't find your name, it's because hundreds of forms are still being properly formatted for this view, so check the webpage regularly. However, you can see how this unique database will work with the sampling of records that people have given permission for Polio Australia to publish. Those who have not given permission are being added to anonymous aggregate data – but the numbers still count!

In time, the Australian Polio Register will undoubtedly become a powerful tool for both social research and posterity alike.

Keeping in touch

Why not join the likes of the "*The Bill and Melinda Gates Foundation*" and register to follow Polio Australia's [Twitter](#) feed? And check out what people are saying on our [Facebook](#) page. So much technology, so little time!

Information for Seniors

[Seniors.gov.au](#) is the Australian Government's premier source of information for Australians over 50. It provides a single point of access to Government and non-Government information and services for older Australians.

In addition to providing a huge range of factual information relevant to older Australians, [seniors.gov.au](#) provides a variety of community-building features. These features enable you to interact with other people with similar interests and ensures that this online resource reflects the opinions and addresses the issues of direct relevance to Australians over 50.



Poliomyelitis after a twelve year incubation period

[Virology Blog](#) — 30 June 2011

Analysis of poliovirus recovered from the stool of a patient with fatal poliomyelitis revealed that she had been infected with the virus 12 years earlier, probably when one of her children received the oral poliovirus vaccine. This case has the longest known incubation period for vaccine-derived poliomyelitis, and highlights our still rudimentary understanding of how poliovirus causes disease.

The patient in this case, a 44 year old woman from Minnesota, had been diagnosed with [common variable immunodeficiency](#) (CVI) in 1991. Patients with this disease lack B lymphocytes and therefore cannot produce antibodies that help control microbial infections. For example, individuals with CVI often develop chronic enterovirus infections. Furthermore, after receiving oral poliovirus vaccine, CVI patients may shed infectious virus for long periods of time, often in the absence of clinical disease. To help control infections, CVI patients are regularly given pooled immune globulin harvested from healthy individuals.

The patient's first symptoms were cough, runny nose, malaise, and low grade fever, which resolved in 4 days. Two days later she experienced leg cramps which lead to leg weakness, a fall, and hospitalization. The weakness spread to the upper extremities and involved severe muscular pain. Respiratory failure developed and the patient died after 92 days of hospitalization. The initial mild disease, followed by neurological symptoms, is a [classic course of poliomyelitis](#). Read the full story [here](#).

The End of Polio is within reach



Together we can make it a reality. According to the [Global Polio Eradication Initiative](#), our generation stands on the brink of eradicating the second human disease in history. Polio – a disease which has disabled millions and pulled individuals further into poverty – has been reduced by 99% over the past 30 years, and its end is within our reach. Global efforts have delivered incredible progress: immunising more than 2 billion children and saving more than 5 million children from life-long paralysis or death. But right now the critical work of the Global Polio Eradication Initiative is constrained by a US\$590 million funding gap, putting this historic opportunity at risk.

Help build the public support needed to help make the end of polio a reality. Add your name to [the petition](#), calling on world leaders to help end polio forever. You can also hear an interview with WHO's Chris Maher about this Initiative on ABC Radio National's "Life Matters" [here](#).

Is Polio Eradication Slipping Out of Reach?

by [Maryn McKenna](#), Wired Science, 26 July 2011

The long effort to wipe the paralyzing disease from the planet, begun in 1988 by a coalition of the World Health Organization, the Centers for Disease Control, UNICEF and the service organization Rotary International (recently joined by the Bill and Melinda Gates Foundation), has several times missed its goal of interrupting all transmission of wild virus — first in 2000, then in 2002 and then again in 2005. The hoped-for date has been moved again, to the end of 2012 this time.

But last week, an [independent assessment bluntly warned](#) that the international effort "is not on track to interrupt polio transmission as it planned to do by the end of 2012" and likely will miss that goal as well.

Because the eradication effort has been going for so long, and operates so far out of the awareness of most of the industrialized world, it's important to say why the campaign ever got started. Polio spreads easily: The virus enters the body via the mouth, replicates in the gut, and passes out of the body in feces — and thus poses a risk of transmission in any situation where the organism is present and sanitation is poor. It causes at least partial paralysis in roughly 1 of every 200 victims, usually young children. Read the full article [here](#).

[Polio this week](#) as of Wednesday 27 July 2011

Source: *Polio Global Eradication Initiative*

| Total cases | Year-to-date 2011 | Year-to-date 2010 | Total in 2010* |
|-----------------------------|-------------------|-------------------|----------------|
| Globally | 286 | 576 | 1349 |
| • in endemic countries: | 96 | 73 | 232 |
| • in non-endemic countries: | 190 | 503 | 1117 |

Did CIA undermine global health by faking vaccines in hunt for bin Laden?

by [Tom Paulson](#), [Humanosphere](#) – 12 July 2011

One of the chronic problems the international community has with almost every disease-fighting campaign has been the need to overcome mistrust — mistrust of government, of foreign health workers or outsider do-gooders in general. This is, for a variety of reasons, especially true of vaccines.

So many worry that such global health efforts will suffer from the revelation, reported first in [The Guardian](#) and later by the [New York Times](#) and others, that the Central Intelligence Agency (CIA) set up a fake vaccination program in Pakistan in order to collect DNA samples.

Says The Guardian:

The CIA organised a fake vaccination program in the town where it believed Osama bin Laden was hiding in an elaborate attempt to obtain DNA from the fugitive al-Qaida leader's family, a Guardian investigation has found.

The CIA has refused to confirm or deny these reports. Read the full story [here](#).

Pakistan intelligence agencies had no role in hiding bin Laden

774 Melbourne ABC Radio — 19 July 2011

One of the members of the Pakistani Board of Inquiry looking into the US, CIA (Central Intelligence Agency) backed raid on the city of Abbottabad where Osama bin Laden was killed says he's absolutely certain that neither Pakistan's intelligence agency, ISI (Inter-Services Intelligence), nor the military, had any idea bin Laden was holed up in the city. General Nadeem Ahmed is a member of the Pakistani Board of Inquiry. At his home in Rawalpindi he spoke to Jon Faine, from 774 ABC Melbourne, about the inquiry and the CIA's manipulation of the polio programme. Read more [here](#).

Historical photos wanted

Polio Australia would like any 'polio days' photos (*sample right*) so they can be uploaded onto our website to expand our historical collection. If you would like to see your old photos online, please scan (300 dpi minimum), save each as a .jpg file, and send them attached to an email to: photos@polioaustralia.org.au.

Oral History of Polio in Australia

by Dr Mary Westbrook

The social impact of polio in Australia is being documented by the Oral History and Folklore Branch of the National Library of Australia, Canberra. The aim of the project is to investigate both the social impact of polio at the time of the epidemics as well as during the period after the decline of polio in Australia and when the late effects of polio emerged. This is being done through 20 or so 'whole life' interviews of polio survivors and of others involved in the epidemics such as nurses. Unfortunately available funding has limited the number of interviews that can be conducted.

Last year the National Library advertised for an oral social historian to conduct the interviews. The contract was awarded to Frances Rush, an oral historian, and Mary Westbrook who is a polio survivor and researcher. Mary is a member of the NSW Post-Polio Network and is a member of the Clinical Advisory Group of Polio Australia. Frances has been conducting the interviews with polio survivors which usually take place over several days. Mary has been advising on the planning of the project and relevant issues in polio survivors' experiences that the interviews need to cover. With such a relatively small number of interviews it is considered particularly important to ensure that participants represented as wide a range of survivors as possible. Thus we wanted participants who contracted polio in the different epidemics.

The oldest interviewee who is aged 95 contracted polio when she was two years old. The Tasmanian epidemic of 1937 is especially memorable as it had the second highest per capita rate of infection of all the polio epidemics worldwide. We looked for survivors who contracted polio at different ages, who differed in the severity and type of polio symptoms they exhibited, who underwent different types of treatment for polio, and who were left with varying residual effects from polio. We wanted both male and female participants, survivors from different ethnic backgrounds and from various locations in Australia. All interviewees had to have contracted polio in Australia. Polio Australia's President, Gillian Thomas, and the State Post-Polio Networks have assisted in the identification of possible participants. At the conclusion of the project interviews will be available on the website of the National Library.



News from Polio Quebec

At their last board meeting, the directors studied the definition for *universal design* proposed by the Accessibility Challenge Group (GDA) - a research group with the University of Montreal.

The definition put forward advocated that "*Universal access is the characteristic of a product, process, service, information or environment which in the interest of fairness and an all-inclusive approach, allows anyone to act independently while achieving equivalent results.*"

For [Polio Quebec](#), this definition encompasses all the variables that characterize accessibility without limiting the focus to the disabled. It also reflects the importance of an inclusive approach that allows anyone, regardless of their status, to participate actively in a social, economic and cultural environment.

[Post-Polio Canada](#) is a non-profit organization which aims to support and inform its members as well as raise awareness of the medical network and the general population with late effects of post-polio syndrome.

NB: This concept of universal design is definitely something that needs more consideration, doesn't it? Accessibility is so fundamental and logical but often so hard to find! Unfortunately, it always seems to be about the additional cost of making something accessible that comes first!

Polio-World Photo Contest

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.

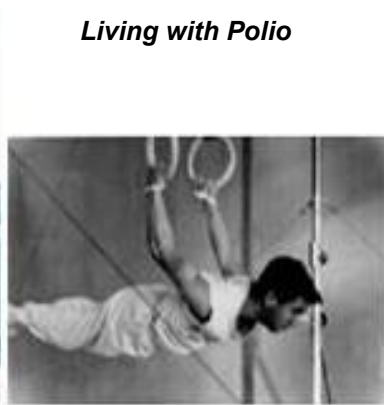
Polio-World will use the photographs to create an awareness of post-polio and to show the world that WE ARE STILL HERE!

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 below*), and attach your three photographs.

Deadline is 1 September 2011 — Be CREATIVE!



Polio



Living with 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.

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](#).

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