

**POLIO NSW INC**

*formerly Post-Polio Network (NSW) Inc*

# NETWORK NEWS

*Incorporating – Polio Oz News*

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## President's Corner

Gillian Thomas

As foreshadowed in my report last issue, in June Polio Australia organised a visit to Canberra en masse to reiterate that "We're Still Here!", and to lobby about the inequity of the 65-year-old age limit for entry into services available through DisabilityCare Australia. Polio survivors are particularly affected by this discrimination because many of us are already over 65, or will be by the time services are available nationally from 2018. With our visit to parliament planned for the last week of the winter session, this was expected to be the last chance before the election to get the ear of Government and Opposition MPs and Senators. However, as Mary-ann wrote in her introduction to the Winter Edition of Polio Oz News: "*They say that timing is everything, and Polio Australia certainly picked an historic day to visit Parliament House! Alas, on Wednesday the 26th of June, the corridors were not abuzz with word that the post-polio campaigners were there – rather that the country was about to have a leadership change on that very day, of all days!*".

Polio NSW members were well represented in Canberra with more than half of the 37 attendees coming from NSW and the ACT – the Committee thanks you very much for your support. Polio Australia has set up a "We're Still Here!" website <[www.stillhere.asn.au](http://www.stillhere.asn.au)> where you can read the stories of a number of the campaigners who travelled to Canberra from across Australia, together with a full report on the campaign. Also on this site is a copy of the "Proposal to Support Polio Survivors" which the campaigners presented to the parliamentarians with whom they met. Polio NSW and Polio Australia will continue to lobby for funding for long-overdue support services for you and keep you up to date with our efforts.

The presentations by Dr Peter Nolan at our AGM last December were so extensive that it has proven difficult to do them justice via a written report only (although the editors are still aiming to report highlights of the presentations for *Network News*). We are pleased to advise, therefore, that videos of Dr Nolan's talks, together with copies of his slides, are now available online on the Polio NSW website. Please visit this page <[www.polionsw.org.au/seminar/nolan](http://www.polionsw.org.au/seminar/nolan)> to access the material.

Polio Australia is delighted to have been given the opportunity to field a team in Northcott's "Walk With Me" fundraising event being held in Parramatta on Friday 13<sup>th</sup> September. Our team's name is "Parramatta Promenade" – you are invited to join the team as an active participant, or support its efforts through donations. See the last page of this newsletter for more details. Without government support, fundraising like this is essential to ensure the continuation and enhancement of Polio Australia's services for polio survivors. In particular, a community development worker for each state is a priority to assist the State Polio Networks.

Thank you to all who have renewed your membership with Polio NSW so promptly, and to those who also donated so generously. We are still processing the high volume of renewals currently being received and so if you have recently sent in your subscription your address label may not yet have been updated to reflect this.

Finally, the annual Polio Australia *Health and Wellness Retreat* is coming back to NSW next year! The St Joseph's Centre for Reflective Living in Baulkham Hills has been booked for 8<sup>th</sup> to 11<sup>th</sup> May 2014. Further details will be provided in upcoming issues of *Network News* but we wanted to give you advance notice of the dates so you can put them in your diary now. This will be the fifth Retreat that Polio Australia has organised – to read about the format and content of the highly-successful previous Retreats, check out this page on the Polio Australia website: <[www.polioaustralia.org.au/retreats](http://www.polioaustralia.org.au/retreats)>.

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## EnableNSW – What are your experiences?

Those able to access DisabilityCare Australia should find it easier to obtain aids and equipment (also known as assistive technology) to help them remain independent in the community. Currently, eligible residents of NSW with a permanent or long-term disability are provided assistive technology through the Department of Health's EnableNSW program. At this stage, we do not know how assistive technology will be delivered through DisabilityCare Australia. We are interested, however, to hear members' current experiences (positive and negative) with EnableNSW in respect of your access to such technology in the areas of mobility, self care and respiratory support. *For example:* For how many years and/or how often have you accessed EnableNSW (previously known as PADP – Provision of Aids to Disabled People)? How successful have you been in applying for aids and equipment? Have you been able to obtain the items you need to assist your day-to-day living and participation in the community? Have the costs to you been reasonable? How long have you had to wait for your aids or equipment after submitting a completed application? Have there been hurdles you've had to overcome in the application process, the prescription process, or in the provision or maintenance of the equipment? Has an application you've made for aids and equipment been rejected? If so, have you lodged an appeal against the rejection, and with what result? Do you have any other comments you wish to make? Please send your responses to our office by email or mail. All information you give us will be treated confidentially and only anonymous aggregate data will be used in any report we produce based on the contributions we receive.



## Vale – Mary Le Clair

by Gillian Thomas

We were saddened earlier this year to learn of the passing of long-time member, Mary Le Clair. Mary was a well-respected Communication Consultant who arrived in Australia from Canada in 1973, having contracting polio in 1959 at the age of 22. Mary was an active member of Polio NSW, both in delivering workshops and contributing to *Network News*. She presented a Public Speaking Seminar to members in February 1991 and the skills we learnt still stand us in good stead today. Mary was also a presenter at our 1996 International Conference "*Living with the Late Effects of Polio*". Her topic was "*How to Record an Oral History of your Experiences and your Thoughts About Polio*". The workshop was well attended and proved to be, as Mary had promised, "fun and cathartic". Mary's presentation was later published in *Network News*, Issue 57, February 2003 (copy available on the Polio NSW website).

Mary was an avid scooter user and in searching my *Network News* archives I came across a number of contributions from her on this topic. In 2002 Mary gave some tips to fellow members about what to take into account when purchasing a scooter, and was available to speak to any member seeking more information. In 2005 we became aware of several members who were being disadvantaged, they believed inappropriately, by the NSW State Transit Authority's decision to refuse access to buses for those using 3- rather than 4-wheeled scooters. As a confident and safe long-term user of a 3-wheeled scooter, Mary decided that she was going to put up a fight about this policy and sent us a copy of the letter she had written. In her covering note to us, Mary wrote in part: "*So here I sat twiddling my thumbs or taking a taxi everywhere, watching these big bright expensive buses drive by. Twiddling my thumbs is rather pointless so today I am composing this letter and sending a copy to each and every person who is prepared to help get this policy reviewed: RTA, Sydney Buses, the Minister of Transport, newspapers, my local Council, my local state and federal members, TV channels and pertinent organisations.*"

Mary thought nothing of packing up her scooter and heading off on an overseas adventure. In 2008 she wrote to us and said: "*Travelling is not the problem in Peru. Trying to get into a bank with a scooter can get you into trouble though. The bank security guard called the local constabulary when I "questioned" going in. I was told it was because there may be a bomb in "the machine" !!*". Of course, Mary then took the opportunity to ask the policemen to pose with her for a photograph (published in *Network News*, Issue 76 – again, a copy can be obtained from the Polio NSW website)!

**We are very grateful that Mary's daughter, entertainer Lisa Budin, is holding a fundraising benefit concert for Polio NSW in memory of her mum and we know it will be a very fitting tribute. The concert will be held at the Parramatta Leagues Club on Saturday, 26<sup>th</sup> October – full details are on page 7. We encourage you and your family and friends to come along – you'll enjoy a great night's entertainment and support Polio NSW into the bargain.**

# A Statement about Exercise for Survivors of Polio

*Reprinted from Post-Polio Syndrome: Identifying Best Practices in Diagnosis and Care. PHI & IVN. Vol. 19. No. 2, 2003 – Original source: "March of Dimes" 2001*

**Advising all polio survivors not to exercise is as irresponsible as advising all polio survivors to exercise.**

Current evidence suggests that exercises are often beneficial for many polio survivors provided that the exercise program is designed for the individual following a thorough assessment and is supervised initially by knowledgeable health professionals. Polio survivors and their health professionals who are knowledgeable about the complete health status of the individual survivor should make the ultimate decision on the advisability of exercise and the protocol of the exercise program.

Clinical research studies support exercise programs that are prescribed and supervised by a professional for many polio survivors, including those with the symptoms of post-polio syndrome.

Acute paralytic polio can result in permanent muscular weakness when the viral infection leads to death of anterior horn cells (AHCs) in the spinal cord. Recovery from paralysis is thought to be due to the re-sprouting of nerve endings to orphaned muscle fibers creating enlarged motor units. Recovery is also attributed to exercise that facilitates the enlargement of innervated muscle fibers. For example, some polio survivors regained the use of their arms and have walked for years with crutches. Others regained the ability to walk without the aid of braces, crutches, etc., and have continued to walk for decades.

The increased muscle weakness recognized in those with post-polio syndrome is believed to occur from the degeneration of the sprouts of the enlarged motor units. The premature death of some of the AHCs affected by the poliovirus is speculated to also cause new weakness, and some new weakness is caused by disuse, or a decline in activity or exercise.

**There is agreement that repetitive overuse can cause damage to joints and muscles, but can repeated overuse and excessive physical activity accelerate nerve degeneration or nerve death? This is the crux of the physical activity/exercise debate.**

Physical activity is movement occurring during daily activities. Exercise is defined as planned, structured and repetitive body movement.

Therapeutic exercise is conducted for a health benefit, generally to reduce pain, to increase strength, to increase endurance and/or to increase the capacity for physical activity. **Polio survivors who over-exercise their muscles experience excessive fatigue that is best understood as depletion of the supply of muscle energy.** But some polio survivors' weakness can be explained by the lack of exercise and physical activity that clearly leads to muscle fiber wasting and cardiovascular deconditioning.

**The research supports the fact that many survivors can enhance their optimal health, their range of motion and their capacity for activity by embarking on a judicious exercise program that is distinct from the typical day-to-day physical activities.** These same polio survivors need not fear "killing off" nerve cells, but do need to acknowledge that the

deterioration and possible death of some nerve cells may be a part of normal post-polio aging.

**Exercise programs should be designed and supervised** by physicians, physical therapist and/or other health care professionals who are familiar with the unique pathophysiology of post-polio syndrome and the risks of excessive exercise. Professionals typically create a custom-tailored individualized exercise program that is supervised for two-four months. During this period, they will monitor an individual's pain, fatigue and weakness and make adjustments to the protocol, as needed, to determine an exercise program that a polio survivor can follow independent of a professional.

**When designing a program, these general principles are followed to achieve specific goals and/or maintenance levels.**

- The intensity of the exercise is low to moderate.
- The progression of the exercise is slow, particularly in muscles that have not been exercised for a period of time and/or have obvious chronic weakness from acute poliomyelitis.
- Pacing is incorporated into the detailed program.
- The plan should include a rotation of exercise types, such as stretching, general (aerobic) conditioning, strengthening, endurance or joint range-of-motion exercises.

**Polio survivors who experience marked pain or fatigue following any exercise should hold off doing that exercise until contacting their health professional.**

Researchers and clinicians cannot make a more definite statement until additional studies on the long-term effects of exercise and the effects of exercise on function and quality of life are undertaken.

### **Criteria for diagnosis of post-polio syndrome**

**Prior paralytic poliomyelitis with evidence of motor neuron loss**, as confirmed by history of the acute paralytic illness, signs of residual weakness and atrophy of muscles on neurologic examination, and signs of denervation on electromyography (EMG).

**A period of partial or complete functional recovery** after acute paralytic poliomyelitis, followed by an interval (usually 15 years or more) of stable neurologic function.

**Gradual or sudden onset of progressive and persistent new muscle weakness or abnormal muscle fatigability** (decreased endurance), with or without generalised fatigue, muscle atrophy, or muscle and joint pain. (Sudden onset may follow a period of inactivity, or trauma or surgery.) Less commonly, symptoms attributed to post-polio syndrome include new problems with breathing or swallowing.

**Symptoms persist for at least a year.**

**Exclusion of other neurologic, medical and orthopaedic problems as causes of symptoms.**



# Neurogenic Bladder - What Are My Options

By Richard Daggett, Downey, California – [richard@polioassociation.org](mailto:richard@polioassociation.org)

Reprinted from the Post-Polio Health Newsletter, Vol. 29, No. 2, Spring 2013 – [www.post-polio.org](http://www.post-polio.org)

If you've ever attended a post-polio support group, or participated in a conversation with another polio survivor, you might hear this question: "*Do you think my pain is related to polio?*" The answer: "*It might be related, but it might not be related.*"

In recent months I asked myself a similar question, and gave myself a similar answer. But, since I am incurably inquisitive, I decided to try to find a more satisfying answer to the question, "*could this be polio related?*"

I had a severe case of bulbospinal polio at age 13 in 1953 and was in a tank respirator (iron lung) for about six months. Although I had a moderate recovery, I was still visibly disabled – impaired pulmonary capacity and walked with a noticeable limp. And, as with many of us, I've had my share of post-polio issues.

About a year ago I began feeling that something wasn't right. For more than a month I had mild nausea, bloating and general malaise. I just didn't feel well. My primary doctor was on vacation, so in desperation I went to a local emergency unit. I must have looked dreadful because they saw me right away.

After an exam and an abdominal x-ray, the doctor came into my cubicle and said, "*You look like you are seven months pregnant.*" He wasn't smiling. It turns out I was retaining urine – three liters of urine!

It must have been building up over time. I had no pain and I thought I was urinating well – at least as well as any man my age. I was given a Foley catheter and I made an appointment with my urologist for the next day. The urologist said we should wait a couple of weeks, with the catheter in place, and then he would do some tests.

When I returned, he did a cystoscopy and a complete urodynamic study. This was uncomfortable, but not very painful. He said the tests indicated I had a neurogenic bladder. I learned that a neurogenic bladder is a dysfunction that results from interference with the normal nerve pathways associated with urination. Hmm. Normal nerve pathways? Polio?

When I asked my urologist if this condition could have anything to do with polio, he said he doubted it, but seemed open to the idea. Most polio-related medical literature describes polio as a disease of the motor nerves. But having had bulbar polio, I know that polio damage can include more than just skeletal muscles. I began a serious search of available medical literature to see if I had missed something in my previous studies.

As I was searching I learned that a good friend had also been diagnosed with this condition and also had to have a Foley catheter. We are about the same age, and both of us had bulbospinal polio. And, in the past few months, I have heard of others with varying degrees of neurogenic bladder. Talking to these polio survivors re-awakened memories of my polio onset. I remembered being catheterized at the same time I was put in the tank in 1953. I remember telling the doctor I didn't need a catheter, and he replied, "*You might need one pretty soon, and I'd rather we do this before you need it.*" These memories encouraged me to continue my research.

I found several references to neurogenic bladder on the Internet, and some of these mentioned polio. Almost all of these sites said something similar to: A neurogenic bladder is the result of interrupted bladder stimulation at the level of the sacral nerves. This may result from certain types of surgery on the spinal cord, sacral spinal tumors, or congenital defects. It also may be a complication of various diseases, such as syphilis, diabetes

mellitus or poliomyelitis.

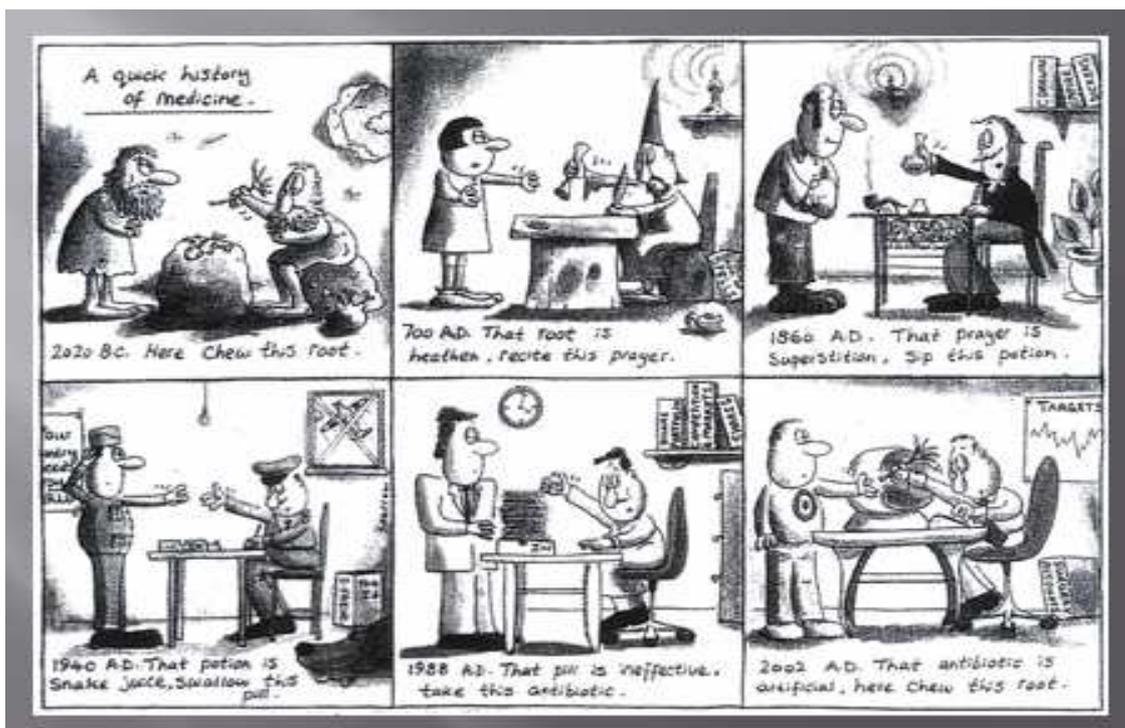
This was a partial help, but none of these references pointed to any reasons for polio to impact the bladder muscles. The only two published medical articles I could find were references in the *Journal of the American Medical Association* in 1948 and the *Journal of Urology* in 1936.

Regardless of the cause, the next question for me was what were my treatment options? The obvious first step was the indwelling, or Foley, catheter placed while I was in the ER. This eliminated the urine retention. This also brought almost instantaneous relief from my nausea and malaise. After I stabilized and all the tests were completed, my urologist suggested intermittent catheterization. This procedure requires that a person insert a disposable catheter several times a day. Because of my limited arm and hand strength this was very difficult for me. It was also fairly uncomfortable.

I have been using a Foley catheter, replaced monthly, for about one year. It is not recommended to use one beyond that length of time because of the risk of infection, erosion of urethral tissue and other complications. If my urethral Foley catheter needs to be discontinued, a relatively common solution is to have a suprapubic catheter. This is an outpatient procedure to place a catheter into the bladder through a small incision in the lower belly. My friend with the neurogenic bladder has had a suprapubic catheter for several months and has had no problems. It is much more comfortable than the urethral catheter.

Another possible treatment is a 'pacemaker' for the bladder. The one I have researched is the Medtronic InterStim®, used to treat incontinence and also retention problems. This small apparatus uses wires surgically implanted in the sacral nerves to stimulate the bladder muscles. Based on my research, I am not inclined to have such a surgical procedure at this time.

Decision time is rapidly approaching, and I will make my decision in consultation with my urologist. I welcome feedback from other polio survivors, and will post a medical update in a future issue of Post-Polio Health.



# Serenading 50's, 60's, 70's Show



## POLIO NSW FUNDRAISING BENEFIT CONCERT

In memory of Mary Leclair ( Lisa Budin's Mum)

SATURDAY 26<sup>TH</sup> OCTOBER 2013

PARRAMATTA LEAGUES CLUB

11-13 O'Connell St, Parramatta

SHOW STARTS 7PM

Tickets: \$28.00 book through Lisa Budin 0430 050 548 or email: [lisabudin1@hotmail.com](mailto:lisabudin1@hotmail.com)

Or through Roseanna Gallo 0418 692 410 email: [roseanna@rgmusic.com.au](mailto:roseanna@rgmusic.com.au)

Or purchase tickets through the Parramatta Leagues Club PH: 8833 0777

The Polio NSW committee are very excited about this upcoming fundraising benefit concert to be held on Saturday 26<sup>th</sup> October 2013 and we would like to thank Lisa Budin for all her support in organising this fundraising charity event. This concert is in memory of her mother Mary Le Clair, a long-standing member of Polio NSW.

Lisa is a renowned singer and entertainer and has performed her *Remembering the Carpenters* show at many venues including the Sydney Opera House. Lisa also stages Senior Concerts at venues throughout Sydney. Visit her website at [www.lisabentertainment.com](http://www.lisabentertainment.com).

The fee for hiring the function room at the Parramatta Leagues Club has been generously waived by the Directors of the Club; we are very appreciative of this gesture and for their continued support of Polio NSW.

So, please make every effort to gather your family and friends together and attend this concert in support of Polio NSW. Bookings can also be made by phoning the Polio NSW office on 02 9890 0946.



*In Memory of  
Mary LeClair*



# Sexuality and the Disabled

by Anne Buchanan, Publicity Officer, Polio NSW Committee

Following the recent release of the movie “The Sessions”, your Committee was approached by several members who suggested that “Sexuality and the Disabled” would be a worthwhile topic at a seminar.

After some discussion at the February Planning Meeting, it was decided that the sensitive nature of this topic made it difficult to be certain that it would attract a sufficient number of attendees to have a speaker on the subject.

We have, however, conducted some research into the matter and this has revealed quite a bit of information which may be of interest to members. For instance, did you know that “The Sessions” is not the only movie on the subject of sexuality and the disabled? A documentary called “Scarlet Road” follows the work and efforts of Australian sex worker, Rachel Wotton. Ms Wotton specialised in working with clients with a disability and realised that there was, and still is, a huge need for the type of service she provides. This became a passion which she followed and extended into efforts to increase awareness of, and access to, appropriate sexual expression for people with disabilities.

Her endeavours to bring greater understanding of the needs of disabled people and the work she does led Rachel to be involved in setting up an organisation to help fulfil this need, and so Touching Base began in the year 2000. It is an Australian charitable organisation and offers information and advice for people with disabilities or their carers on how to connect with a suitable sex worker. They also provide training for sex workers wishing to specialise in disabled clientele as well as training for disability service providers, and the organisation has a very comprehensive website.

As members can appreciate, the subject topic itself covers a huge range of issues, each with its own very individual circumstance and solution. It is therefore respectfully suggested that anyone who would like information on the subject of sexuality and the disabled, or who has an interest in the work being done in this area of the disability movement, view the Touching Base website <[www.touchingbase.org](http://www.touchingbase.org)>. In the event you would like more specific details on a particular matter, there are links given on the website where you will be able to find further information.

It is also worthwhile noting that Royal North Shore Hospital offers a service whereby information and advice is readily available by phoning their main telephone number (02 9926 7111); and Independent Living Centre has a section on their website which may also prove useful to some people <[www.ilcnsw.asn.au](http://www.ilcnsw.asn.au)>.

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## Polio Post



***Theraquatics Equipment*** has sent their catalogue of products for warm water exercise and rehabilitation. They also specialise in equipment for the disabled swimmer. Their equipment can be purchased on-line at <[www.theraquatics.com.au](http://www.theraquatics.com.au)>.

# One doctor's dream: to keep India's last polio ward empty

by Jeremy Laurance

Reprinted from Eastern News – March, 2013. This is an extract, the full article can be found at [www.independent.co.uk/life-style/health-and-families/health-news/one-doctors-dream-to-keep-indias--last-polio-ward-empty-8517409.html](http://www.independent.co.uk/life-style/health-and-families/health-news/one-doctors-dream-to-keep-indias--last-polio-ward-empty-8517409.html)

*Polio once claimed thousands of victims a year in India. But it is two years since the last case. Jeremy Laurance discovers why:-*

After 20 minutes navigating the foetid alleyways of Old Delhi's market looking for someone to mend the broken winder of my watch (repair cost: 65p), I was picking my way through the river of humanity flowing down Chandi Chowk, the main shopping street, when a man perched on a toy trike emerged from the crowd and hurtled down a steep kerb straight towards me grinning crazily. As I dodged and glanced down I glimpsed a pair of twisted limbs sticking out at an impossible angle, ready to fell all comers.

Was he a polio victim? Almost certainly. Many of those who crawl along the city's streets dragging useless limbs, begging for alms certainly are. They are a living memorial to a disease already banished from the West – and a warning of what lies in store should it ever return.

In the early 1990's there were 3,000 cases of paralytic polio each year in India. Now there are none.

In a country of 1.2 billion people, the monumental scale of that achievement – successfully vaccinating 95 per cent of children aged five and under – is a tribute to Indian diligence. India's passion for bureaucracy may burden businesses with paperwork (and drive visa applicants to despair) but here has proved it can also save lives.

The centrepiece of the campaign is the national immunisation days (NIDs), begun in 1995, around which all other activities are organised. The aim is to vaccinate 172 million children under five on a single day, employing 2.5 million vaccinators who are moved in 155,000 vehicles (including boats, elephants and camels) carrying over 6 million ice packs (to keep the vaccine cool) and supplying over 700,000 vaccination booths – set up in hospitals, on street corners and out of the back of cars. The NID is followed by a five day mop up phase in which vaccinators move from house to house, following a meticulously planned route, seeking out those missed.

The task is a logistical nightmare. The local distribution centre for Mukundpur, north west Delhi, is in a dingy office in the Jagiwan Ram Government Hospital where the boxes of vaccine are kept in a freezer. At 6:30 am last Sunday the vaccine was loaded into insulated containers with a packet of ice – it must be kept between 4 and 8 degrees centigrade – and dispatched in one of 15 vehicles to supply 160 booths. We followed one of the routes down narrow streets thick with mud after heavy rain, stepping carefully – in the absence of toilets, the roadway must serve. Feral dogs picked over piles of rubbish, water buffalo lolled in a weed-covered swamp nuzzling bags of waste, while a pair of drowned goats floated nearby, their bellies already swollen.

We found the first booth on an empty lot sandwiched between ramshackle breezeblock dwellings – four tables and a few chairs under an imposing red and yellow awning festooned with posters proclaiming in English and Hindi: "End Polio Now".

It was already mobbed with children attracted by two westerners, UK Rotary Club members

from a group of 50 visiting the programme (at their own expense) to see how their donations were being spent – £30m raised since 1985 and counting. They had also come to provide moral support to Indian colleagues whose passion for the cause might be waning after a decade and a half of continuous effort. Their yellow polo shirts and foreign appearance were as big a draw as the plastic balls Rotary provided for each child as a reward.

Your reporter was asked to volunteer and donning the Rotary colours, a yellow and red waistcoat, I held the vial of pink vaccine, lifted straight from the ice bucket, above the head of 17 month old Angel as her father, Raju Chaurasia, 32, struggled to hold her still.

I shook a couple of drops into the nozzle and squeezed. Angel scowled, licked her lips and grimaced (the vaccine has a bitter taste). One down, only 171,999,999 to go.

How did Raju know about the vaccination day? He had seen it on TV. Why had he come? *"She is my daughter, and polio is deadly and I didn't want her to suffer."* Angel had been several times before, he said. In high risk areas such as this the NIDs are followed by local immunisation days, as many as 10 times a year. Maintaining the momentum of the campaign is crucial to success – a country is only declared polio free three years after its last case which will fall in February 2014 in India's case.

Chris Yates, who has been bringing groups of UK Rotarians to participate in the NIDs for almost a decade, described how in Uttar Pradesh, a polio hotspot, a resurgence of the disease in 2007-8 was only curbed when Muslim religious leaders were persuaded to join a committee to promote the vaccine locally.

On a visit to Pakistan he was warned that western volunteers would not be welcome – their presence likely to fuel rumours of a Western plot against the Muslim community.

While India prays polio will not return, for some the vaccine has come too late. The disease robs those afflicted of hope of an independent life – and their families too.

At St Stephen's Hospital in the north of the city, Dr Matthew Varghese runs the only ward dedicated to polio sufferers in all of India, where he attempts to restore independence even to those worst affected, who may have been crippled for decades.

He showed a picture of a young boy whose trunk was so grossly twisted he could sit up only by supporting himself on his hands. His father's wish was that his son should go to school. But as long as the boy needed his hands to support himself, he could not hold a pencil.

*"My dream is to make sure this ward remains empty"*, Dr Varghese said.



### **Memorials:**

*Since our last newsletter we have become aware of the passing of one of our members:*

Clem Fields

### **Thank You:**

*We would especially like to acknowledge the recent significant financial donations given to Polio NSW by:*

the many members who have generously donated when renewing your membership – your support is greatly appreciated

# Ask a Post-Polio Specialist #3

With Vance C Eberly MD, Rancho Los Amigos National Rehabilitation Center Downey, California  
Reported by Mary Clarke Atwood. Editorial assistance by Richard Daggett and Vance Eberly, M.D.  
*Rancho Los Amigos Post-Polio Support Group Newsletter, June 2011*

*Reprinted with permission of Rancho Los Amigos Post-Polio Support Group, Mary C. Atwood*

At our December 11, 2010 meeting with Vance Eberly MD, orthopedist in the Rancho Los Amigos Post-Polio Clinic, he answered questions that were submitted in advance and also from the audience. The questions and answers included in this report are:

- What are the most frequently asked questions at the polio clinic?
- Do I have post-polio syndrome (PPS)?
- Can you give me the medication to get rid of this problem?
- What are your thoughts on stem cell therapy for PPS?
- What are your thoughts about blood pressure and post-polio?
- How are muscles graded?
- Can I exercise?
- What are the general guidelines for hip replacement surgery?
- How can the pain of an arthritic hip be treated?
- In scoliosis, would wearing a corset prevent further curvature?
- What are your thoughts on cholesterol lowering drugs and PPS?

## **What are the most frequently asked questions at the polio clinic?**

Those questions are about diagnosing PPS and medications.

## **Do I have post-polio syndrome?**

Post-polio syndrome (PPS) is a clinical diagnosis based upon a person's history and functional decline over time; it is a diagnosis of exclusion. There is no blood test to confirm it. The bottom line is that you had polio (probably in your early years) and had some weakness, even sub-clinical weakness, and you recovered from it. You lived your life for 10 or more years at a certain level of function and then noticed your level of function was declining a little.

You may have noticed some of these possible changes, which are similar to a reversal of the compensatory mechanisms from acute polio.

- fatigue
- muscle weakness
- muscle pain, muscle cramps, muscle atrophy
- joint pain
- cold intolerance
- problems swallowing
- maybe you have to sit up to catch your breath
- speaking in shorter sentences and similar things

When all other conditions are ruled out as the cause, there is a clinical diagnosis of PPS.

The original polio affected the anterior horn cells in the spinal cord which go to your muscles. Those are the nerves that go out from your spinal cord to make the muscles work. Polio killed some of those cells and damaged others.

A muscle without a nerve is useless, it just sits there. That is like a motor in your car without the electrical system making it do what it normally does. If you take away that car's electrical system the motor doesn't work. Over time that motor will just rust. That is what the muscles affected by polio basically do also.

With our body being a biological system, we try to compensate for that. Some of the nerve cells were killed, so the remaining nerves try to branch out and go to other muscle fibers to help compensate and get them to do what they normally do. Then the neuron (nerve) is going to more muscle fibers than it normally does, it is doing more than it usually does over a lifetime, and it wears it out sooner. It will not necessarily last as long. When you have a neuron that has been damaged by polio and it tries to do more than it should be doing, those are the ones that are dropping off over time and you develop PPS.

### **Can you give me the medication to get rid of this problem?**

Unfortunately there is no medication to treat PPS. In reviewing the literature you can read about trials for neurotransmitters, neurotransmitter uptake blocking agents, growth factors, growth hormones, anti-inflammatories, anabolics to try to build muscles – but none of those work.

If you really look at the cause of polio, then it will make sense that none of these drugs will really work. Polio affected the motor neuron cells; it killed a certain number of them and it weakened others. So you have these damaged or lifeless nerve cells. Taking any of these medications is not going to change the weakened or lifeless nerves. There will never be a pill to solve the problem.

### **What are your thoughts on stem cell therapy for PPS?**

The “pill” that everyone is looking toward today is stem cell therapy. Dr Eberly believes that stem cell therapy will have limited usefulness for people with the late effects of polio.

If you were a child going through your growth years and got polio, and it affected the muscles and you have muscle weakness, then all the other tissues don't experience the normal stresses they would. Frequently there will be leg length discrepancies, hypertrophic development of the joints and of the bones. Over time there will be joint contractures.

The muscles that those nerves once innervated have been non-functional for many years and become fibrotic. They are replaced with scar tissue and fat. Over time, a muscle that has not been worked for many years, regardless of the cause, is not going to work anymore once you try to fire it back up.

So if stem cells are placed in the spinal cord, and for example the nerve axon finds its way all the way down to the calf muscle, that calf muscle is not going to be working, even if it is innervated. It is a worthless muscle at this point in time. Then the joints are still going to be contracted and you are still going to have all of the problems associated with long term denervation of the muscle.

With that said, stem cell therapy will not be completely useless for the late effects of polio. Dr Eberly thinks that polio survivors who have bulbar symptoms, where polio affected the brain stem, might have these symptoms:

- breathing difficulties
- swallowing problems
- central fatigue where they are chronically tired
- decreased concentration

In the future, people with these symptoms might benefit from stem cell therapy.

Dr Eberly does not know of any ongoing stem cell research for PPS right now. The important thing is that stem cell research is happening. Once it is optimized, stem cell therapy will probably be applied to every disease state. Researchers don't necessarily have to be looking at PPS currently, because in the future they will be able to apply what is learned to other diseases.

### **What are your thoughts about blood pressure and post-polio?**

Blood vessels are smooth muscles and not affected by polio or PPS. Many primary care physicians do not have much background in polio and treating PPS. Generally speaking, exercise is good for helping control hypertension. If you are in a wheelchair most of the day, your muscle strength is such that activities of daily living are probably sufficient exercise for that person.

### **How are muscles graded?**

Muscles are graded from five to zero. A grade five muscle is normal strength. The grading then goes down 4, 3, 2, 1, 0. A muscle graded zero is flaccid paralysis. However, this is not a linear scale.

When you go down from a grade 5 muscle to a grade 4 muscle, you do not lose 20% of the strength – the loss of strength is actually about 50% to 60%. When you go from a grade 4 muscle strength down to grade 3 it is similar – another 50% to 60% loss. At grade 3 you are basically down to about 20% to 25% of normal strength, which is what is needed for activities of daily living.

### **Can I Exercise?**

People who had polio and whose muscle strength is globally about 25%, then activities of daily living are exercise for those people. If they go out and try to exercise, then they run the risk of developing PPS because they are making those nerves work much harder than they should. Remember, you have damaged nerves doing more than they should. If you really push them you are going to wear them out sooner and it is going to make you weaker by doing exercise rather than making you stronger. That weakness is permanent – it is not recoverable because you killed off those nerves by overworking them.

If a person is thinking about starting an exercise program, Dr Eberly recommends that you first have a manual muscle test (MMT) done by a good physical therapist. Then look at the MMT results. If most of those muscles are grade 3 or less you should not be doing an exercise program. However, you should also avoid doing nothing, because a weak muscle group can be made weaker by disuse. So there is a fine line for those with existing muscle weakness.

People who have PPS usually know their bodies and understand what they can and cannot do. Exercise is based upon your muscle strength. Sometimes a small amount of exercise is good. It all depends upon the individual, and everyone is different.

## **What are the general guidelines for hip replacement surgery?**

Hip replacement surgery is for someone who has hip arthritis. The hip hurts a lot, and the medications don't work.

The important aspect for someone who had polio is that you need to have adequate strength around the hip to hold that ball in the socket. If you don't have that muscle strength, and you have the replacement, the hip will dislocate. A chronically dislocating hip is much more painful than an arthritic hip.

The muscle group on the side of the hip that lifts the leg out should be about grade 3 or 3+ or better. The patient should be able to hold his leg out against gravity for about a count of 10. If you can do that, there is no reason why you cannot have a hip replacement. If you cannot hold that leg out that long, then you should not have a hip replacement because you really run the risk of having an unstable hip. That is far more problematic than the hip arthritis itself.

## **How can the pain of an arthritic hip be treated?**

Treatment for pain in an arthritic hip is limited. First you try the different anti-inflammatory drugs. Keep in mind that anti-inflammatories are the only class of drugs that work for some people and not for others. So you try one and if that doesn't work then you try the next one.

A hip injection can be done periodically for arthritic pain relief. That has to be done under fluoroscopy because the hip joint is so deep and so well covered by bone that you have to demonstrate that the needle is actually inside the joint before you inject steroids in it. That procedure might be done three or possibly four times a year.

When you have polio you do not have nerve pain, but you may have muscle pain and/or joint pain.

## **In scoliosis, would wearing a corset prevent the continuation of the curve?**

It depends upon where the curve is and how big the curve is. For a severe curve the corset itself will not help. You would need to have a TLSO (Thoracolumbosacral orthosis) clamshell type thing which is very uncomfortable to wear.

## **What are your thoughts on cholesterol lowering drugs and PPS?**

If you have elevated cholesterol and a cholesterol lowering drug is recommended by your physician, take it. If you develop a side effect where it affects your muscles then you should stop taking it. This is the same as with the general population.

*These answers help us better understand some of the challenges facing polio survivors as they grow older. Our thanks to Dr Eberly for so willingly providing answers to these questions. We appreciate his time, effort, and humor.*

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*"When I read this article, I believed it expressed so well the hopes and benefits people with disability dream of receiving from the NDIS (or Disability Care Australia (DCA), as it is now known) as well as the risks which must be avoided. Thank you, Peter Perry, for succinctly articulating what DCA will mean to us. At present those people with a disability over 65 are not eligible to receive funding through the DCA, but for those who are eligible, their dreams could be fulfilled."* Nola Buck, Co-Editor

## ***2013 will be a year unlike any other***

*by Peter Perry, CEO, Spinal Cord Injuries Australia (SCIA)*

*Reprinted from the ACCORD Newsletter, Autumn 2013.*

*ACCORD is the quarterly publication of SCIA which is committed to doing whatever it takes to create and maintain relevant services for people with physical disability.*

*Visit <[www.scia.org.au](http://www.scia.org.au)> or call 1800 819 775 for more information about ACCORD and SCIA.*

The biggest game in town this year for organisations like ours and our members is the launch of the National Disability Insurance Scheme (NDIS) and its little-publicised cousin, the National Injury Insurance Scheme (NIIS). The NDIS will commence from July this year with an initial group of around 10,000 people in the Hunter regions, with the full implementation of the scheme in NSW to be done progressively between now and 2018. The NIIS will cater for the needs of newly-injured people from July 2014. Even though we have argued in the past that there should only be one scheme, we did not win that argument.

The early statements out of the government and those charged with establishing the NDIS have been promising. Issues such as not defining people by their disability, a focus on the effect of a disability rather than its cause, and an emphasis on individual decision and choice rather than impairment and diagnosis, are all promising early signs. Ultimately, if everyone who qualified for the scheme is able to receive sufficient funds to overcome the obstacles that they themselves identify as preventing them from having opportunities in life that are no different to the rest of the population, then the scheme will have achieved its true purpose in line with our obligations under the UN Convention on the Rights of Persons with Disabilities. This is a human right based reform, not an economic reform – although there will be major economic benefits, and any initial cost to the budget will be more than recouped by society in future years through higher taxes, lower pensions, and less social dislocation and exclusion.

As with any major reform, there are risks. Trying to change the way that more than 400,000 people interact with the many thousands of organisations (both old and new) which provide their services will be a major undertaking and we will not see this scheme settle down into a stable pattern for at least ten years. During that period of transition, there will be many stories of people being exploited, services going broke, a decline in the social capital that has been built up over many years, people with money not being able to access the services they need, with others being dazzled with slick marketing campaigns and seemingly endless choice. Although this may sound horrible, it's very familiar to me – I used to work in finance, after all! All of these risks are part of daily life in our capitalist society, and if we want people to have true choice, then the emergence of risks such as these are an inevitable consequence.

However, there are two things that should not happen as these inevitable risks emerge. Those who are most exposed to exploitation and abuse should not be left to fend for themselves, but must have appropriate protections, in the same way that all citizens are protected by things such as consumer legislation. And we must be vigilant to ensure that those making decisions about the scheme don't lose their nerve, and stay true to the

scheme's original vision. It would be easy for a future politician to make some expedient decisions about the scheme to get some problems out of the headlines, but we could lose so much if this were allowed to happen. Unfortunately, despite the best efforts of those involved, schemes such as the Lifetime Care Scheme in NSW have evolved to be paternalistic entities which provide little choice and control to their clients, due to the design of their funding, the rules under which they operate, and the rigid medical model of disability which they apply.

We all must ensure that any chinks that appear in the direction of the NDIS and NIIS are quickly identified and repaired, in a sustainable fashion. Only in this way can we be sure that people will truly be able to attain control over their own lives. Not much to ask is it?



## *Seminar Report - Maintaining Our Independence - 9th July*

*by Susan Ellis, Co-Editor*

Our midyear seminar was held at Northcott in Parramatta and was attended by 48 members. Three guest speakers presented interesting and sometimes amusing topics and all seemed to enjoy the day of learning, discussion and companionship. As usual a number of people contributed to the organisation of the day and a thank you must go to Alice Smart, who ran the raffle and provided morning tea; to George Laszuk, who ordered a scrumptious lunch and dealt with many last minute tasks; to the office staff, who handled registrations; to Gillian Thomas and Nola Buck, for introducing our guest speakers; and to Merle Thompson, our gracious 'giver of gifts' to the presenters.

**Dr Diane Bull:** Diane is well known to our members as she has been a past Polio NSW committee member and has presented at past seminars and our 2010 Retreat.

Diane holds both a Bachelor of Science and a Bachelor of Science (Honours First Class) degrees and a Doctorate of Philosophy from the Faculty of Medicine. She is a registered Psychologist (MAPS) and a Director of the *forethought consultancy group* which deals with all aspects of psychology.

For the past 35 years Diane has held positions at the University of Newcastle including Deputy Dean and Senior Lecturer and Postgraduate Supervisor in the areas of Health, Psychoneuroimmunology, Clinical and Experimental Methodology.

Her research over the last 30 years has progressed from laboratory based research to an applied field of investigating the parameters of immune responses and other factors of wellbeing under condition of both physiological and psychological stress.

Diane is also a polio survivor.

"It's not all about Age" was the title of Dr Bull's presentation. How often are we told that it's just old age? 100 years ago the average life expectancy was 40, today we have an 85% chance to live to be over 80 due to technical and medical advances over the last 50 years.

### **Ageing Aspects of Development**

Development does not end with the attainment of physical maturity. It is a continuous process extending from birth through adulthood to old age. "**From Womb to Tomb**". Physical and emotional changes occur throughout life, affecting the individual's attitudes, cognitive processes, and behaviour.

Human development involves continuous interaction between **heredity** (biological predispositions determined by one's genes) and **environment** (the experiences encountered while growing up in a particular family or culture).

## Physiological Aspects of Ageing

As in the case with infant development, much of the development of adulthood is dependent upon the physical changes that ageing bring. Most of these changes have little functional significance, but because physical attractiveness is so valued by most societies, many view dealing with ageing people with less enthusiasm than they might otherwise in similar interactions with younger people.

Obvious changes such as wrinkles, greying hair, baldness, weight increase, can alter how we behave or more importantly, how others behave to us. Just as one tends to act in a certain manner in response to the physical aspects of an infant, one often reacts to preconceived ideas to older looking people.

Other physiological changes affect behaviour in later age. Senses are more likely to decline. This could certainly restrict much activity and the ability to follow many pursuits.

**Vision** – acuity, presbyopia, glare tolerance, adaptation to light, etc.

**Hearing** – sensitivity to high frequency sound decreases, particularly to men over 55, and in people over 75 notable hearing losses in at least three quarters of those tested.

There are marked changes in hormonal functioning with ageing. Middle aged men experience hormonal changes which are gradual. At around 50, female menopause is experienced with more marked physiological change (loss of menstruation, lack of fertility, etc). However, 90% of women will have no major effects from menopause.

This period for females was once seen universally as being a severely emotional and stressful event. It is now clear that the majority of women experience little psychological stress through menopause and those that do often have an expectation that it is "expected". Perceptions regarding menopause are changing – with a once unmentionable subject, it is more often seen as a passage of strength rather than weakness.

Other normal behaviours are affected by age. The total amount of sleep and the proportion of rapid eye movement (REM) sleep both change, with most older people needing less of both non-REM and REM sleep, with often the pattern changing to having shorter periods of sleep but more often. However, there are individual differences.

Most of us remember few if any events before the first five years, but children of less than four years learn to walk, put on clothing, and perform skills that will last a lifetime. Similarly, many old people often have great trouble recalling recent memories but can manage to learn new skills (eg using a cane) or adapt old skills.

In both regards, infant and ageing memory resembles that of people with hippocampal damage. Perhaps infants have memory problems because the hippocampus is slow to mature, whereas old people have memory troubles because the hippocampus and related structures are slowly deteriorating.

During adulthood, the number of active neurons decline in varying areas of the brain. It is a normal part of the ageing process, and it appears not to be a contributing factor to such abnormal conditions as **senile dementia**, which occurs in approximately 15% of people over 65 years.

The prefrontal cortex also deteriorates in old age. The deficits may be due in part to a declining number of dopamine and norepinephrine synapses in this area. Other crucial neurochemicals implicated are glutamate and acetylcholine.

In ageing, calcium channels become somewhat 'leaky' resulting in a higher than normal resting level of calcium, which may block stimuli from neurons. The loss of neurons in ageing is also hastened by exposure to corticosterone, a hormone the adrenal glands release during stressful periods. **Stress has one of the biggest effects on ageing.** So RELAX! Corticosterone does not damage the neurons, but it increases the metabolic activity of the cells, making them more vulnerable to damage by other toxic substances eg from smoking – cigarettes contain a lethal cocktail of over 400 chemicals such as acetone, carbon monoxide, arsenic, nicotine, butane, methanol and hydrogen cyanide. **Smoking has the biggest effect on health and ageing.**

## Ageing and Personality

Some researchers suggest that personality is laid down early in life, and once set it is quite durable. However, other researchers suggest that the evolution of personality continues throughout life. **"I've always been like that", your personality is set for life – NOT TRUE. Most traits can be learnt (and unlearnt), in the same as new skills are learnt.**

How can the difference of whether personality is stable or continually evolving be reconciled? It appears to depend on what particular time in the lifespan the study is done, and what is used as a measure of personality.

Some personality is characterised by both stability and change. Some personality traits tend to remain stable – emotional stability, extraversion, and assertiveness. Other aspects tend to change systematically as people grow older – masculinity, femininity.

In later adulthood both sexes typically become more androgynous, resulting in the unisex of later life. Men become more nurturing, tender and emotional. Women tend to become more assertive and self-confident (standing up for themselves where in the past they might have put up with things, now if something is not right they will speak up).

Generally, if a marriage has lasted 35+ years it is likely to last forever as a couple have individually developed into 'people' – not wife and husband but 'us'.

There are many instances of personality changes from, for example, young radicals becoming ultra conservative in later years. For example, many of the radical political activists of the 1960's are now either senior business people or conforming politicians (Gates, Jobs, Tom Hayden, Abbott etc).

There are three basic personality dimensions:

**Neuroticism** – anxiety, worry, hostility and depression.

**Extroversion** – outgoing, active, and assertive.

**Openness** – receptiveness to new experiences, new ideas, changing one's life as well as one's mind.

*Openness is the best type, being more adaptable. Openness will make you happy and accept that change is good. As polio survivors we have had to accept polio-affected changes, not just ageing changes. We might be upset that we can't do certain things but we have learnt to deal with it – we can choose to be upset OR to be happy.*

These people (openness) are less likely to be affected by the 'stress' of the situations.

What one of us might consider a crisis, another might view as a challenge or adventure.

Characteristics such as agreeableness and conscientiousness are other traits that have been found to be stable over time.

Behavioural traits (personalities) are NOT concrete over a lifespan – "*I've always been like this*". Individuals gradually recognise and attempt to remedy the weak parts of their personality. Some learn to control their tempers or learn to express their anger constructively.

In general, traits that are undesirable within a particular culture tend to become less prominent with age, while desirable traits show more consistency. In our culture, as people mature they generally become less neurotic and more open to ideas.

Certainly senile dementia is an obvious example that can alter our personalities (behaviour), but there are often more subtle causes. For example, living with a chronic disease such as polio, arthritis or other illnesses that involve long term intractable pain can be quite taxing, and can often lead to personality (behavioural?) changes.

## **Cognitive Aspects of Ageing**

Adult cognition can be studied in several ways:

**Developmental (stage perspective)**

**Psychometric (measurement of abilities)**

**Information processing**

**Developmental:** According to some theorists, there appears to be a small decline in some cognitive ability after the age of 60 but this is area specific.

There is a suggestion that age-related decreases in the ability of the working memory may be the underlying factor for the decrease in both the speed and other changes in aged adults' memory function. Although mental speed declines with age, problem-solving ability remains mostly unimpaired if older people are given adequate time to complete the task (the getting of wisdom!). *Studies do not measure wisdom, wisdom is learnt from experience eg things are not black and white, we might ask 'what decision do I make from all my experiences'*.

We suspect part of this loss of speed may reflect the increased cautiousness that adults develop. That is, adults may be less inclined to attempt a wrong answer for the sake of speed and prefer to take longer to ensure correctness, which could be seen as more important than reaction time.

Although research is still in the initial stages, it seems that the erosion of processing speed is a slow, lengthy process beginning in the middle years of adulthood.

**DEMENTIA:** "*Dementia is a part of Alzheimer's and is NOT forgetfulness*". Although dementia is more likely to occur among the aged, it can occur before old age. At the same time, it is by **NO MEANS** an inevitable occurrence of old age, even among the very old.

## ESTIMATED PREVALENCE OF DEMENTIA

AGE	PREVALENCE
65-69	2%
70-79	6%
80-84	12%
85-89	22%
90+	41%

*Based on studies in Japan, Australia, New Zealand, Britain, Sweden and Denmark*

To avoid dementia keep the brain active, learn new skills and challenges, do not become isolated in your home, get up and out, belong to a group and reach a happy healthy old age.

### The Joy of Ageing

To illustrate that degeneration of cognitive and physical ability is not a function of age let's revisit the achievements of some old codgers:-

1. At 100, Grandma Moses was painting.
2. At 94, Bertrand Russell was active in international peace drives.
3. At 93, George Bernard Shaw wrote the play *Farfetched Fables*.
4. At 91, Eamon de Valera served as president of Ireland.
5. At 91, Adolph Zukon was chairman of Paramount Pictures.
6. At 90, Pablo Picasso was producing drawings and engravings.
7. At 89, Mary Baker Eddy was directing the Christian Science Church.
8. At 89, Arthur Rubinstein gave one of his greatest recitals in New York's Carnegie Hall.
9. At 89, Albert Schweitzer headed a hospital in Africa.
10. At 88, Pablo Casals was giving cello concerts.
11. At 88, Michelangelo did architectural plans for the church of Santa Maria degli Angeli.
12. At 88, Konrad Adenauer was chancellor of Germany.
13. At 85, Coco Chanel was the head of a fashion design firm.
14. At 84, Somerset Maugham wrote *Points of View*.
15. At 83, Aleksandra Kerensky wrote *Russia and History's Turning Point*.
16. At 82, Winston Churchill wrote a History of English Speaking People.
17. At 82, Leo Tolstoy wrote *I Cannot Be Silent*.

As polio survivors, we have already shown the world what we are capable of, so let's continue the **CELEBRATION OF LIFE!**



**Sue Gorman:** Sue is the Project Officer – Advocacy Support for IDEAS (Information on Disability and Education Awareness Services). IDEAS is a specialist information service that provides sustainable information on disability to support inclusive communities. IDEAS works to support people with disability and people with age related disability, their families, carers and other supporters to self-advocate, enabling them to make informed decisions about matters of importance to them. This is achieved by providing a range of free information services and products. The IDEAS Disability info Line is a free telephone information service for people. Ask us the questions, we give you the answers and you make the decisions. Phone 1800 029 904, Text 0458 296 602 <[www.ideas.org.au](http://www.ideas.org.au)>. **Real people, real listening.**

Sue gave a brief history of how IDEAS was started in 1981 in the Riverina region of NSW. A polio survivor and member of Polio NSW, Jenny Stanzel was involved and subsequently was employed by IDEAS. IDEAS' head office is in Tumut with offices in Ultimo and Wollongong. IDEAS host an EXPO every two years to promote new ideas, services, exhibitions, displays and workshops.

Every day you or someone you care for might need help to see, hear, learn, speak up or get around. IDEAS provide free information to help you get the services you need.

IDEAS has a database which is updated every 12 months with files on suppliers, equipment and on travel (list of accessible accommodation throughout Australia). Feedback about suitable or non-suitable accommodation is appreciated. IDEAS received 450 phone calls per month with recent enquiries about changes to NDIS. A newsletter is produced every 2 months with 2,000 readers; to get a free copy (electronic or hard copy) phone 1800 029 904.

Sue told us how IDEAS was able to help a couple from NSW who wanted to drive to Adelaide to attend their son's wedding; the wife was a wheelchair user. Sue was able to create an itinerary of suitable accommodation for them and to help problem solve for them along the way with hiring of some equipment as well.

Sue also told of some disabled students who needed support teachers in high school and found that their needs were not being met. Sue was able to advocate on their behalf and get the one-on-one support that they needed.

IDEAS is funded through the NSW state government. If you need advice on how to access different government departments or programs, for example, HACC (Home and Community Care), or how to get subsidised modifications to your home, or community nursing, or a podiatrist, then IDEAS can help. IDEAS can also act as an advocate to give you a voice when dealing with any problem.

IDEAS can help you find services available: Some of those services might be:

- |                              |                                  |
|------------------------------|----------------------------------|
| ✓ Community Supports         | ✓ Holiday and Recreation Options |
| ✓ Help with Your Rights      | ✓ Housing Options                |
| ✓ Subsidies and Entitlements | ✓ Accessible Tourism             |
| ✓ Respite                    | ✓ Life Skills                    |
| ✓ Easy Transport             | ✓ Personal Care                  |
| ✓ Help at Home               | ✓ Special Education              |

*"When you call IDEAS, we must keep what you tell us confidential. We will give you information for free and not ask for anything back. Our information officers **listen** and then carefully give you the answer to your question however you want to receive it: by phone, post or email. We give information that is broad and deep and local so that you make the best decision for yourself. What is unique about IDEAS is that we are independent."*

Call **TOLL FREE**: 1800 029 904

SMS: 0458 296 602

Email: [info@ideas.org.au](mailto:info@ideas.org.au)

Website: [www.ideas.org.au](http://www.ideas.org.au)

**Rebecca Howard:** Rebecca Howard is a senior Occupational Therapist at the Independent Living Centre NSW and has over 13 years clinical experience in the health and disability sectors. Rebecca presented on how the Independent Living Centre provides services to people across NSW. She brought practical examples of assistive technology equipment and demonstrated how to use the ILC NSW website <[www.ilcnsw.asn.au](http://www.ilcnsw.asn.au)>. The Independent Living Centre NSW, which recently relocated to Blacktown, is a leading information, education and advisory centre for Assistive Technology and the built environment. The ILC NSW provides information and impartial advice to individuals about assistive technology solutions and choices for independent living. **The Independent Living Centre NSW - Changing Lives through Assistive Technology**

## **The Independent Living Centre NSW (ILC NSW)**

ILC NSW is a leading information, education, and advisory centre for Assistive Technology and the Built Environment. ILC is located in Westpoint Shopping Centre, Blacktown, has plenty of parking and is accessible to public transport.

The built environment includes the physical environment in which we live in but can also extend to how we set our environment up with services and supports.

ILC NSW is an information and advisory service. They do not sell products or assess or prescribe, but they have a diverse staff on the team that can assist you with impartial advice on aids, equipment, home modifications and ideas that allow people to exercise choice in their home, school, and work and in the community. They offer impartial advice and information with up to date information on over 10,000 items, services, equipment and aids, giving you a choice of options. If they don't have a solution to your problem/need then they will research until they do have a solution for you. It is ILC NSW's aim to create independence by finding options and solutions.

The staff consists of a number of Occupational Therapists (OTs), a speech therapist, their CEO is a physiotherapist, they have an access consultant who is also a builder and is in a wheelchair too so he can bring perspective from a number of sides when looking at the built environment. They have a number of administrative staff who have worked in the area of disability for a number of years. They believe they have a really good and diverse team, with a range of skills to provide the user with the best information.

ILC's Occupational Therapists are available (by appointment) for up to an hour; they do not offer an assessment of your medical condition but use their clinical skills and input to make suggestions of what might be useful to you. They offer impartial advice and can provide a choice of information on a particular product and where to purchase this product in your local area.

If a product cannot be found commercially or if it needs modification then TAD (Technical Aid to the Disabled) volunteers are available to design or modify a product to solve the problem.

ILC's access consultant can provide advice on home improvements or alterations, for example, bathrooms, kitchens, ramps, etc.

There is an ILC in every state that provides information specific to each state. They are also part of an international alliance of Assistive Technology Providers, such as DLF in the UK.

**Vision**

*Endless possibilities for all*

**Purpose**

*To provide impartial advice, information and leadership on assistive technology that builds possibilities for choice*

**Values**

*Leadership, Choice, Community, Impartiality*

**Assistive Technology**

Assistive technology is any piece of equipment or system whether acquired commercially off the shelf, modified or customised that allows an individual to perform a task that they would otherwise be unable to do, or increases the ease and safety with which the task can be performed.

**Services Provided by ILC NSW***Information and Advice*

- Visits and Appointments
- Info-line 1300 885 886
- Website and @ Magic Database
- Group Tours
- Community visits

*Social Enterprises*

- ILC Access Consultancy
- ILC Training
  - Accessible Buildings and Environments
  - Assistive Technology Workshops

ILCNSW has products and items on display covering Communication, Mobility, Seating, Self-Care, Dressing, Bathroom, Kitchen, Computers and Recreation. There is a Display Apartment featuring a kitchen, lounge/dining room, bathroom and bedroom.



Rebecca demonstrated how to use ILC's website to research products and aids that might be useful to us in solving some issue we might be having difficulty with eg when showering or dressing.

At the end of Rebecca's presentation she demonstrated a range of gadgets that she brought along to show us. Many were very simple but very effective in solving problems, for example, a jar opener. Some of the gadgets produced a round of laughter from the audience!! Many questions were asked including a solution to sitting in a scooter at a dining table, and an easy solution for doing up a bra or buttons on a shirt, for example.

A few members spoke of how the Independence Living Centre had helped them with advice. Pat Featherstone had wanted to buy suitable lounge chairs that would make standing up from a chair easier and went along to ILC for advice and was able to try out a number of different chairs that were on display. Once an appropriate model was selected, Pat was able to order the chair to suit her needs for now and long into the future and it have been extremely successful.

Nola Buck had concerns with a handrail that was to be installed in her local church and was able to consult with ILC's Access Consultant, Hamish, who gave the correct advice regarding conformance with the Australian Standards which resulted in a functional handrail being installed.

Sue Ellis told of her experience when deciding on her first wheelchair to use when needing to travel longer distances. The OT at ILC was able to not only advise on the size, weight and features that were suitable for her BUT also what was needed to suit her husband who would be pushing the chair eg height of handles, ease of storing into car boot, brakes etc.

Since the Seminar, we have received an email from Harriet Kormer, Client Services Manager at ILC: *"We'd be very happy to host a day at the ILC NSW for your members in the future – and we're available at all times for people to contact our service for help in finding information and advice re assistive technology and the built environment, to help problem-solve issues they may be facing."*



The image is a promotional graphic for the Independent Living Centre NSW. It features a blue header with the ILC logo (a stylized white figure) and the text "Independent Living Centre NSW" and "Changing Lives Through Assistive Technology". Below the header, there are four rows of contact information, each with an icon: a globe for the website "www.ilcnsw.asn.au", a telephone for the number "1300 885 886", an envelope for the email "help@ilcnsw.asn.au", and a house for the address "Westpoint Level 4, Shop 4019, 17 Patrick St, Blacktown NSW 2148". At the bottom right, there is a 3D illustration of several stylized human figures in white and blue, some holding hands, symbolizing support and community.



# 2013-2014 Polio NSW Upcoming Events

<b>Saturday 30 November</b>	Burwood RSL Club 96 Shaftesbury Road Burwood	<b>Annual General Meeting and Seminar</b>
<b>Thursday 8 to Sunday 11 May 2014</b>	St Joseph's Baulkham Hills Centre for Reflective Living	<b>Polio NSW will host the 2014 Polio Health and Wellness Retreat</b>

## Management Committee - Executive Members Contact Details

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Merle Thompson	Secretary	secretary@polionsw.org.au	02 4758 6637
Alan Cameron	Treasurer	treasurer@polionsw.org.au	0407 404 641

### **Committee Members** (for contact details please ring or email the Network Office):

Charles Anderson, Anne Buchanan, Nola Buck, Wendy Davies, Barbara Fuller, Gary Fuller, Alice Smart and John Tierney

## PPN Office and Other Contact Details

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Mary Westbrook	Q's about polio & PPS	askmary@polionsw.org.au	---
Nola Buck/Susan Ellis	Co-editors Network News	editor@polionsw.org.au	---

## Have You Included Your Polio Details on the Australian Polio Register?

The Australian Polio Register was established by Polio Australia in October 2010 to gather information on the numbers of polio survivors living in Australia today, whether or not they contracted polio in this country. There are currently more than 2,000 polio survivors on the Register and this number increases daily. To make the Register truly reflective of the unmet need for polio services throughout Australia, all State polio networks are urging every Australian polio survivor to join the Register which is available on Polio Australia's website at <[www.polioaustralia.org.au](http://www.polioaustralia.org.au)>. The Australian Polio Register form can either be completed online or downloaded (by you, or a friend with internet access) for completion and subsequent return to Polio Australia.

**Important:** Before completing a new registration please be sure to review the "Check Your Entry" page on the Polio Australia website to make sure you haven't previously registered.

# About Polio NSW

The Post-Polio Network (NSW) Inc was formed in 1989 by polio survivors for polio survivors. In 2011 the Network changed its name to Polio NSW Inc but our services for polio survivors remain unchanged.

Polio NSW is a self-help, self-funded organisation governed entirely by volunteers. Polio NSW provides information about polio's late effects and supports those who may be affected now or in the future. We conduct regular Seminars and Conferences, publish *Network News*, foster the establishment of regional Support Groups throughout NSW and the ACT, and maintain a comprehensive website.

Polio survivors, their family members and friends are all welcome to join Polio NSW, as are health professionals and anyone else who supports our aims. Membership provides information and support that can maximise the physical and psychological quality of life of polio survivors and their families.

If you live in Australia, we can post you a free Information Kit and Membership Application Form. The Kit includes a copy of our booklet *Helping Polio Survivors Live Successfully with the Late Effects of Polio* which explains the late effects of polio and details the many benefits of Network membership. This booklet can be emailed to those enquiring from overseas.

The annual membership subscription (payable in Australian dollars only) is \$10 not employed or \$20 employed. On first joining, new members also pay a \$5 once-off joining fee. Those initially joining between 1 April and 30 June in any year are deemed to be financial until 30 June the following year. Membership renewal is due on 1 July each year and members are alerted to their financial status with each Network mailing. Over 80% of Polio NSW's income, which is used to provide its services, comes from membership subscriptions and donations.

## Resources for Members

On joining Polio NSW, members are issued with free resources including a brochure *Hospital, Medical And Dental Care For The Post-Polio Patient – A Handy Reference*, and a *Medical Alert Card* which can be carried in the wallet.

Polio NSW also stocks various publications which further describe the late effects of polio and their management. The prices quoted below are for members and postage is included. To order, just write to us – please make cheques / money orders payable to Polio NSW Inc.

<b>Books etc (* indicates Post-Polio Network publication)</b>	<b>Size</b>	<b>Cost</b>
<i>Managing Post-Polio: A Guide to Living and Aging Well with Post-Polio Syndrome</i> <b>Second Edition</b> Edited by Lauro S Halstead MD ( <i>see description below</i> 📄)	288 pages	\$40.00 <i>incl 10% GST</i>
<i>A Practical Approach to the Late Effects of Polio</i> Charlotte Leboeuf	39 pages	\$2.50
* <i>Living with the Late Effects of Polio</i> Conference Proceedings, edited by Gillian Thomas	170 pages	\$29.00
* <i>Polio – A Challenge for Life – The Impact of Late Effects</i> Report: Survey of Members, Merle Thompson	54 pages	\$12.00
* <i>Post-Polio Network - Helping Polio Survivors Live Successfully with the Late Effects of Polio</i> , Dr Mary Westbrook	12 pages	\$3.00 <i>1st copy free</i>
Polio NSW has for sale a four-colour enamelled badge featuring a stunning polio virus design. The badges are suitable for men or women. Each badge comes with a description of the virus and information about Polio NSW. Not only is the badge a great fashion statement, it is an innovative way to promote Polio NSW.	23 mm x 23 mm	\$5.00 <i>plus \$1 postage</i>

### 📄 ***Managing Post-Polio: A Guide to Living and Aging Well with Post-Polio Syndrome (Second Edition)***

*The second edition was published in 2006. Editor Lauro Halstead writes about the rationale for this edition:*

As with the first edition of *Managing Post-Polio*, the major goal of this volume is to summarize the best advice available to diagnose and manage PPS in an easy-to-read, authoritative format for polio survivors, their families, and friends, as well as for health care professionals. The majority of contributors to this book are either polio survivors or experts who have worked closely with polios in clinical settings.

Another important objective of the earlier edition was to reach as wide an audience as possible – an objective that far exceeded our expectations with more than 15,000 copies in circulation. As news about PPS spread, the demand for more information continued to grow. This new edition is in response to that continued demand for information. Also, we have added a new theme to this edition – aging with disability, as once again polio survivors are “pioneers” – the first large group with a chronic physical disability to undergo aging. Since the initial edition, we are all nearly 10 years older, and, hopefully wiser. Quite possibly, we are also more disabled and, therefore, more challenged. It is my hope that this book will help guide us as we journey along this new path together.

Audio tapes of many of the Network Seminars and Conferences held since 1989 are also available at reasonable prices. For further details please contact the Office.



# Polio Oz News

March 2013 – Autumn Edition

## Thinking Ahead with Housing

**by George Xinos**

*Principal Consultant*

[Functional Access Solutions](#)

For most people, the purchase or renovation of a home can be the single biggest investment they make in their lives and one which has an enduring influence on the way they live. All of us need to think and plan ahead when approaching such a significant undertaking, be it whether we have a young family which will grow and eventually leave the family home, or an older person who understands that their physical needs will change and so too will the type of home they need to live within.

Having current difficulties with mobility, movement and strength further highlights the need to plan ahead for any changes which may occur or can be anticipated. Planning to accommodate for a wheeled walking aid now might not accommodate using a wheelchair later.

There are a number of resources out there to help, with many of the ideas and suggestions in them appearing

in different forms across these. Some of these have been provided below.

An enduring Australian Standard which seems to be the source of many of these ideas is *AS 4299 (1995) Adaptable Housing*. 'Adaptable Housing' as



defined by the standard, intends to provide a means for housing to be easily and cost-effectively adapted to the needs of any user. The premise is that by implementing the recommendations set out in this standard, relatively little additional initial cost should allow minimum inconvenience

and cost in later modifications.

The circulation and areas set out in the standard are largely informed by *AS 1428 Design for Access and Mobility* parts 1 and 2. It should be noted that the research that these standards are based on are aging themselves and there have also been some questions raised with regard to how valid the research was to begin with. The importance of including suitable professionals in the process, both therapists and designers, who understand your specific needs cannot therefore be understated.

The most costly changes in any remodelling of a building are generally structural changes, and these standards provide some guidance in planning around this issue. For example a 1.2m clear width is generally required on a path for a person using a wheelchair to be able to independently travel along. Doors require additional circulation depending on the direction of swing and the direction from which a wheelchair user approaches the door from.

*Cont'd P 3*

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Representing polio survivors throughout Australia

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**From the President**



Dr John Tierney  
President

Although I have been involved with Polio Australia since its inception, and served as its Patron and pro-bono government lobbyist, this is my first time in the role of President. Of course, Gillian Thomas is still doing as much as ever in her new capacity as Vice President, so not a lot has changed as we all continue to do our best for Australia's polio survivors. This includes giving evidence at the NDIS Senate Inquiry in Canberra earlier this month. The NDIS is a pivotal opportunity for us and we have certainly been working hard to make sure our voices are heard. And with this being an election year, now is definitely a good time to lobby government, so I encourage everyone to speak with their local Members and Senators to drive home the point that polio survivors receive little or no support, and that we need special programs to manage the Late Effects of Polio. With only 9 months left until the 3 year donation which pays for staff salary runs out, Polio Australia faces the additional challenge of securing funding to ensure we can continue to provide the services and programs you have come to expect. After all, who else is going to do it? A financial commitment by the government would certainly show their true support! 🌟

**From the Editor**



Mary-ann Liethof  
Editor

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March already, and although it's now technically Autumn in the Southern hemisphere, in Melbourne Victoria we've been sweltering through more than 9 consecutive 30°C plus days - which is record breaking - and not a drop of rain. If only we could drain some of Queensland's flood waters away for them!

The next couple of months are set to be quite exciting for Polio Australia, with the fabulously creative "Touched by Polio" art exhibition and fundraising auction being launched on 27th March (see p 6) and the 4th Polio Health and Wellness Retreat taking place in mid-April (contact me to check if any places left - p 18).

As Australia is one of the many Western countries experiencing an increasingly ageing population, the two very different articles discussing putting some thought into accessible

housing (cover story), and Canadian Audrey King's touching tribute to her late mother (p 8), will both strike a chord with many readers, I'm sure.

Speaking of ageing, the keenly anticipated National Disability Insurance Scheme (NDIS) comes under critical review by the post-polio community as we struggle with the inequity of an age 65 cut off on the premise that the aged care system will cater for everyone's needs . . . Polio Australia has been strongly advocating for this criterion to be abolished, as very few polio survivors would have access to the NDIS otherwise.

We hope you enjoy the read. 🌟

*Change is a measure of time and, in the autumn, time seems speeded up; what was is not and never again will be; what is, is change.*  
~ Edwin Way Teale ~

## Thinking Ahead with Housing (Cont'd)



Addressing these considerations now will have a dramatic effect on the bottom line for any refurbishments later.

Larger builds of course also make for more expensive builds. Circulation spaces can be shared to minimise the amount of space required. This can be achieved by designing 'open plan living, dining, kitchen or even study spaces which can lend circulation to each other in general use.

Another strategy could be to plan for the removal of internal walls to achieve a similar

outcome later. Laundries and bathrooms are often placed together to reduce the cost of running plumbing service to multiple areas within a home. Planning the removal of a wall between the two can increase the circulation available to the toilet, shower, basin and washing machine at a later time. To make this as efficient and cost effective as possible however, any wall to be removed should be constructed without any plumbing and electrical services and should not be load bearing. Having your designer or architect produce pre and post adaption layouts for these spaces can assist with getting it right.

Other ideas used in the past have been extending floor finishes under joinery and providing flexible plumbing to enable cheap and easy relocation. Installing additional framing in existing walls to allow the future fitting of grab rails, or a lintel allowing the part removal of a wall to create a 'European style' laundry or study are other examples.

A recent publication which has been gaining additional exposure of late and which provides a lot of useful guidance is the 'Liveable Housing Design

Guidelines' which is freely available at [www.livablehousingaustralia.org.au](http://www.livablehousingaustralia.org.au). Many of the dimensions included in this guideline are derived from the aforementioned standards.

Also worthwhile is the "[Welcome - Design Ideas for Accessible Homes](#)" publication produced and available from the Building Commission in Victoria. It provides simplified diagrams and explanatory information for all areas of a home.

An invaluable resource are the Independent Living Centres (ILCs) present in most states and territories across Australia, which provide useful on-line information and freely available advice from Occupational Therapists and other professionals on staff. Find your local ILC or browse for equipment and advice on their database at [ilcaustralia.org.au](http://ilcaustralia.org.au).

A number of private providers also specialise in housing for people with disabilities and offer a range of services including preliminary planning, design reviews, design and documentation as well as project management. ●

## iDoctor – The Future of Medicine?

**Reporter: Dr Nancy Snyderman**

**Source:** [rockcenter.nbcnews.com](http://rockcenter.nbcnews.com) — 24 January, 2013

One of the world's top physicians, Dr Eric Topol has a prescription that could improve your family's health and make medical care cheaper. The cardiologist claims that the key is the smartphone. Topol has become the foremost expert in the exploding field of wireless medicine. ●

Watch the video interview [here](#).



## National Disability Insurance Scheme (NDIS)

**The NDIS is a hot topic for everyone in the disability sector, with potentially great benefits for people who have, or may acquire a disability in the future - as long as they are less than 65 years of age and already accessing disability services when the scheme is rolled out across the country in 2018. The theory being that anyone over the age of 65 will come under the aged care system.**

Clearly, this criterion is a major sticking point for Australia's polio survivors, who are an ageing, albeit finite, population thanks to the introduction of the Salk and Sabin vaccines in the late 1950's/early 1960's respectively.

Earlier this year, Polio Australia was one of the 1,597 individuals and organisations to put in a [submission](#) into the Inquiry into the National Disability Insurance Scheme Bill 2012, arguing against the aged 65 cut off and highlighting the inability of the aged care system to adequately meet the needs of people ageing with the late effects of polio.

From this submission, Polio Australia was invited to participate in an "NDIS and Aged Care" Roundtable Forum hosted by the Department of Families, Housing, Community Services and Indigenous Affairs in Adelaide, and attended by Minister Jenny Macklin MP and Minister Mark Butler MP (*photo right*). In addition, Post Polio Victoria gave evidence on behalf of polio survivors at an NDIS public hearing held in Melbourne, and Polio Australia's President, Dr John Tierney, and Vice President, Gillian Thomas, gave evidence at another public hearing in Canberra.

Significantly, Polio Australia's evidence on 4 March was widely broadcast in the media, including [this article in The Australian](#).

On Thursday 14<sup>th</sup> March 2013, the House of Representatives passed legislation to set up the Government's NDIS. The NDIS Bill passed with the support of all MPs. Minister Jenny Macklin also moved amendments to the first reading version of the Bill; some of these amendments were made in response to matters raised in submissions to the Senate Community Affairs Committee Inquiry into the legislation.

The [Committee's Inquiry Report](#) was released on March 13. The sections of the report that refer to Polio Australia's submission/evidence and to the Late Effects of Polio and can be found on PDF pages 69, 70 and 72.

At the end of the majority report there is also an interesting section entitled "NDIS Additional Comments - Australian Greens" (*starts PDF page 165*). Greens Senator Rachel Siewert (Deputy Chair of the Committee) made comments about the age 65 cut off, with specific reference to polio, on PDF page 169.

According to the peak disability organisation National Disability Services, the amendments to the Bill (as incorporated in the third reading version) will ensure that all people who are NDIS participants will be able to



Minister Mark Butler and Minister Jenny Macklin

choose to remain in the Scheme after they turn 65; early intervention can apply to people diagnosed with a degenerative condition; and the definition of early intervention will include 'improving functional capacity'.

**It is hoped that these amendments prove beneficial to our cause insofar as polio survivors not being excluded from the NDIS on the basis of age.**

But that, of course, remains to be seen as work proceeds by those responsible for implementing the NDIS.

Appendix 1 to the Senate Committee Report (*PDF pages 181-250*) details (where not confidential) the authors of the 1,597 submissions received by the Committee. Post Polio Victoria's submission is #511 and Polio Australia's submission is #637. All non-confidential submissions can be downloaded from the Committee's website - [click here](#).

Appendix 2 (*PDF pages 255-268*) details the organisations

## NDIS (Cont'd)

(and the few individuals) who gave verbal evidence to the Committee. All this evidence is recorded in Hansard for posterity - [click here for transcripts](#).

The [third reading version](#) of the Bill, which was passed by the House of Representatives, incorporates 77 amendments to the first reading version originally introduced into Parliament on 29 November 2012.

The sections of the Bill which are most relevant to the post polio community at this stage can be found on PDF pages 36-

37, 39-40, and 42-43.

The NDIS legislation will now go before the Senate, anticipated to occur later this month, where the Bill is expected to pass with support from Labor, the Greens and the Opposition.

There were [105 speeches](#) in Parliament between 6 and 14 February and again this week, all supporting the NDIS in one way or another. A number of the speeches mentioned polio and the inequity of the age 65 cut-off. Polio Australia's Vice President, Gillian Thomas, personally wrote to each of the Parliamentarians and thanked

them for bringing our issues to the foreground - this level of awareness shows that our Canberra lobbying efforts over the last several years are now bearing fruit.

So, where to from here for Australia's polio survivors, with particular reference to the age 65 cut-off? As usual, the devil is in the detail. For example, how will the NDIS Rules, which interpret and elaborate on the Bill's Objects and Principles (see PDF pages 16-19 of the Bill), deal with this issue, noting that the Rules are still being developed? Only time will tell. 🌟

## House of Reps Passes NDIS Bill

**Source:** [ABC News](#) - 14 March, 2013

The House of Representatives has passed legislation to set up the Government's National Disability Insurance Scheme (NDIS).

The bill, which will allow the scheme to be launched from July, passed with the support of all MPs. Disability Reform Minister Jenny Macklin broke down as she wound up her speech on the bill.

### Commonwealth funding includes:

- \$342m over three years for individually funded packages for people with significant and permanent disability;
- \$154m over three years to employ local area coordinators;
- \$58m over three years to assess the needs of people with a disability in launch locations; and
- \$240m over four years to build and operate an NDIS IT system

*"This bill is an enormous step in ensuring people with disability, their families and carers, receive peace of mind," she said. "It will bring an end to the tragedy of services denied or delayed and instead offer people with disability the care and support they need over their lifetimes. It will end the cruel lottery that besets people today, where the care and support they receive depends on where they live or how they acquired their disability."*

Ms Macklin says the scheme will initially benefit about 26,000 people in launch sites in five states and territories.

The legislation will now go before the Senate, where it is expected to pass with support from Labor, the Greens and the Opposition.

Proposed by the Productivity Commission, the NDIS aims to shift funding for disability away from welfare to a system based on social insurance, with all taxpayers contributing.

Instead of funding of being allocated to service providers, individuals will instead be given direct access to funding, which they can then administer either directly or through brokers.

The focus of the scheme will be on early intervention, building on the concept that significant initial financial outlay can offset greater costs incurred if problems are left untreated.

The scheme aims to cover 360,000 people with a profound or severe disability, with a separate national injury insurance scheme to cover people who suffer a catastrophic injury. 🌟



# Polio Australia

presents

## *Touched by Polio*

~ from casts to catharsis

*art exhibition and fundraising auction*

*"You could say that Polio is an equal opportunity virus. It doesn't discriminate between generation or gender..."*  
~ Roslyn Dux, Artist ~

**Launched by Senator Mitch Fifield  
Shadow Minister for Disabilities, Carers and the Voluntary Sector**

**Auctioneer - Ross Hedditch**

**Wednesday 27 March / 6:00 pm to 08:00 pm  
Kew Court House 188 High Street Kew Victoria**

**RSVP for catering by COB Monday 25 March  
office@polioaustralia.org.au / 03 9016 7678**

*"Once-upon-a-time tens of thousands of Australian children contracted polio, recovered, got on with their lives (some even became artists!), and they all lived happily ever after."  
~ The End ~*

Or not . . . This exhibition tells a myriad stories through thirty-five 'artified' leg and torso plaster casts.

Many polio survivors have vivid memories of wearing plaster casts to keep their limbs from becoming deformed during recovery and rehabilitation.

Twenty-four artists who have been 'touched by polio' in some way - survivors, family, friends - have contributed thirty-five art works to the "Touched by Polio" exhibition.

**All art works can be found on the "Touched by Polio" Exhibition website  
[www.polio.org.au](http://www.polio.org.au)**



*Bound*  
by Ekaterina Panorgious



*Enduring*  
by Glenys Donnelly



*Equal Opportunity*  
by Roslyn Dux



*The Long Climb*  
by Pauline Derrick

## Vale Dr Jacquelin Perry

**Born: May 31, 1918**  
**Died: March 11, 2013**

Email from [Richard Daggett](#), President, Polio Survivors Association (Los Angeles, USA):

*"I just received word that Dr. Perry died this morning. She was at home, and evidently died in her sleep. She was 94 years old. I saw her recently and she was in good health (for 94 years of age) and full of life."*

### Note from the Editor

In 2008, Jill Pickering (*polio survivor, donor and volunteer*) and I were fortunate enough to meet with Dr Jacquelin Perry in the context of my Churchill Fellowship Study Tour around post-polio institutes in the USA and Canada. Richard Daggett, who had been treated by Dr Perry from childhood through to adulthood, helped to arrange this visit. Dr Perry was definitely an extraordinary woman who has left a huge legacy for polio survivors across the generations.

**The following is an extract from Dr Perry's biography sourced from [Polio Place](#) – a service of Post-Polio Health International.**

*Known among her peers as the Grande Dame of Orthopaedics, Dr. Jacquelin Perry was one of the first ten women to be certified by the American Board of Orthopedic Surgery. She broke new ground in laboratory research by becoming the country's foremost expert on gait analysis. She is co-author, with Judith Burnfield, of *Gait Analysis: Normal and Pathological Function*, the classic text on gait analysis.*

*In the early 1950s, she jump-started the surgical program for post-poliomyelitis patients at Los Angeles' Rancho Los Amigos Medical Center. The medical staff was looking for ways to provide stability for the more significantly disabled polio patients who had paralysis of the neck and trunk. Recognizing that bracing was not adequate, she, along with Dr. Vernon Nickel, pioneered the use of halos for spinal surgery and rehabilitation.*

*Perry's contributions to the body of knowledge of understanding human movement included studying all forms of functional assists from canes, to crutches, braces and wheelchairs. She compared the effectiveness of various forms of bracing and prostheses, total joint replacements, resection arthroplasty and other surgical*



**L-R: Dr Jacquelin Perry, Mary-ann Liethof and Jill Pickering**

*interventions.*

*In 1955, she joined the medical staff at Rancho Los Amigos and was Chief of the Pathokinesiology Service for 30 years. She once stated that her polio experience at Rancho broadened her medical experience (and that of others) because they developed a team concept of patient care; nurses and therapists were encouraged by the physician to take responsibility for evaluation and treatment planning.*

*She was honored with "Woman of the Year for Medicine" in Southern California by the Los Angeles Times in 1959.*

*When polio patients started coming back to her with post-polio symptoms in the late '70s, she counseled them not to push themselves but to modify their lifestyles and implement energy conservation techniques in order to accommodate their new reality. In an article called [General Information Letter for Polio Survivors: Why are "old polios" who were stable for years now losing function? What should they do about it?](#) Perry advises, "Be an "Intelligent Hypochondriac" – Listen to your body and adopt a program that avoids the strain."*

*In 2000, PHI honored Dr. Perry at its 8th International Post-Polio and Independent Living Conference held in St. Louis, Missouri. She, along with Dr. Augusta Alba, was recognized for her dedicated years of supporting polio survivors by combining her medical expertise with practical advice. ●*

Click [here](#) to read the full biography.

Click [here](#) to read **Los Angeles Times** Obituary.

## On Losing a Polio Mom

**by Audrey King**

January 2013

When you are a child you think like a child, like the 9-year-old I was.

Being in a box – an iron lung – trapped in a bed, the horror of food at mealtimes, resolving not to cry during today's therapy, saying goodbye yet again to those who mattered most. Those were the day-to-day dramas that filled my head. There were also some joys: getting up the first time in a wheelchair, going on a picnic with parents, floating to a place in the therapy pool where staff could not reach me that brought a powerful surge of pleasure, a momentary autonomy.

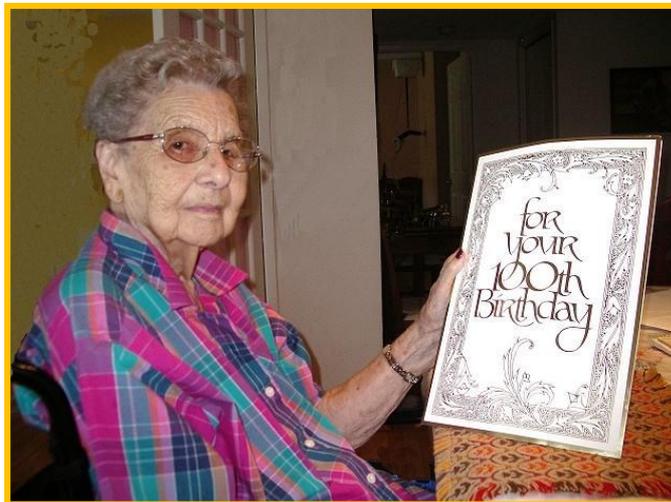
I didn't think about survival, about walking again, the weight of lost dreams, life-long responsibility and dependence. I was but a child.

I had no idea of such things until I grew older, eventually discovering my mother's diary of my early polio years (frequent illnesses, the fight to get me in school, battling authorities, acceptance) and, many, many decades later, finding my own self in a similar place. It wasn't easy for her, a mother of four with an often absent father and no community supports at the time.

The role reversal was gradual. My mother lost her energy and abilities slowly. The changes were so subtle others could not see them, and I began to wonder if the problems were in my head. At first I was puzzled, frustrated, even angry at her illogical, independent episodes. I had no knowledge of aging or

early dementia. But, once I began to understand and to recognize some of my own tenacious traits in her character, to see myself in her, situations often became humorous rather than helpless and much more manageable.

As adults, our mother-daughter relationship had always been one of autonomy and respect for each other. We lived together but had separate



interests. We had no difficulty encouraging and supporting each other's interest to travel and explore new ventures. I was the wage-earner who went out to work each day. She was the homemaker. In many ways, we were good friends.

We discussed major decisions, including what she wanted to do as she got older. I needed to know her choices so that I could honor them, but she could not, would not, broach the subject. I did not want to take over or make decisions for her. Lurking in my past was the knowledge of what it felt like to lose autonomy and control over your own life, to have others assume they know what is best.

If my mother wanted to move to a retirement residence or ultimately a nursing home, we

could begin the process together, but she could not, would not, decide and the months and years ticked by. We applied to a number of nursing homes, but my mother rejected all of them one by one. The time never seemed right.

I increasingly took on the homemaking role through hired help and assumed responsibility for her medical needs and appointments. A major merger was making work life difficult, and I was experiencing post-polio challenges. I had always been able to use my head to overrule my paralyzed body, but exhaustion and overwork led to episodes of serious illness. I had no choice but to give up work.

While I was hospitalized yet again with serious pneumonia and on life support, family members placed my mother temporarily in a nearby nursing home. I visited her on the way home from hospital discharge. She was miserable and desperate to come home. I could not leave her there.

I knew all too well the fear, the feeling of abandonment, the helplessness of nobody listening or understanding. The memories were too powerful, too imprinted on my brain to resist. After all, during those early years many people, including healthcare practitioners, had encouraged my mother to place me in lovely homes that existed for people like me. She had refused and, in doing so, had provided me with family life and opportunities to achieve in both education and career.

As the months went by and my mother's dementia and physical

## On Losing a Polio Mom (Cont'd)

needs increased, I brought in more and more daily help. Often her brilliant wit and reasoning shone through. She didn't want a bath today, NO – she didn't want to eat – why should she? Why were we pushing her around like a child? At times she was quite competent, and it was a challenge to balance competency versus choice.

Giving a person choice, enabling them to be who they want to be and assisting them in doing what they are driven to do – that's what it's all about when it comes to persons with physical disability. How and why is it different for someone whose thinking and reality is altered? Many times she wanted to go to the basement to see if her car was okay, to drive home to Saskatchewan, to start cooking for the family coming back for Christmas. We tried to humor her, but this inevitably frustrated all of us even more and sometimes made things worse.

I realized it was not my mother who was the burden. She just happened to have physical and cognitive deficiencies that come with advanced age. It was the system that I had to battle constantly to get more caregiver hours, to discontinue healthcare specialists that contributed nothing but greater challenge in coordinating appointments and making useless suggestions, not to mention the wasted expense of our health care. It was the multitude of caregivers who left my mother in a mess for the next person to clean up.

I was constantly in the middle. It was like running an office with employees who expected you to solve problems but would not take direction because they were not accountable to you. (The exceptions were the ones I hired who also bore the brunt

and burden of incompetent government-funded caregivers.)

I learned many lessons. I learned how to fight, to charm, to write letters, to be an effective advocate. I discovered the shock value and unimagined power of being a quadriplegic caregiver in a wheelchair.

I periodically wavered in my decision to keep my mother at home with me, especially at the worst of times. Each time I inevitably decided, although it was tough, it was easier for me to keep an eye on her care, intervening and advocating as needed.

Aside from the transportation difficulty of visiting a nursing home on a regular basis, I would have no influence and little awareness of what was happening to her when I was not there. And I already had equipment at home that she could use – a Hoyer lift, an extra wheelchair, a commode, a ceiling track lift over the bathtub. I could teach others in their proper use and supervise.

My long career experience as a psychologist in a rehabilitation setting gave me knowledge of systems, budgets, negotiating skills and human resource techniques that I could use in assisting my mother. How could I not put these skills to use for someone who had invested so much of herself in enabling me to grow and develop and become the person I was?

I learned much from my once proud, independent mother through her inevitable decline. I saw grace and humor in the face of the humiliation and embarrassment her failing body caused her. I marveled at her wit and charm and ability to appreciate what caregivers did for her, even in the face of pain and suffering. Her tenacity and

determination carried her to the end.

She wanted to leave this world. She felt her job was done and she didn't want to be a burden. She said it so many times and in so many ways. But we, and myself in particular, would not listen. We mounted a continuous concerted effort to get her to eat, to get her dressed and out of bed each day when all she wanted to do was sleep and sleep and sleep. It was clearly painful and exhausting.

When she finally left us, I felt relief – for her and for myself. I felt incredible lightness and freedom. The burden was gone for both of us. I felt guilt for not being devastated, distraught, grief stricken. But I realized that I had lost who she was many months before, and my grief and sorrow had been stretched over many years through the heart-wrenching ups and downs of each day. I had already grieved the loss of the marvelous mother she had been.

Guilt about keeping her alive, in spite of her wishes, followed. Was I selfish in not wanting to lose her? Whose life was it anyway? I still ask myself.

When I get old and decrepit enough to consider life not worth living, will those more able than I, who are responsible for my care, listen? Will they hear what I am really asking through my confusion? It isn't quite as simple as having a living will. When you realize someone who loved you so immensely and completely removed the massive boulders blocking your way, forged the path that enabled you to "walk" in her footsteps, it's not easy to let go. 🌈

## Home Medicines Review

**Source:** NPS [MedicineWise website](#)

### Home Medicines Review

Do you know your medicines? If medicines aren't used properly, or if the wrong ones are used together, the results can be serious. Read how a Home Medicines Review can help.

Each year more than 140,000 Australians have to go to hospital with problems caused by their medicine. It has been shown that in up to 69% of these cases the problem can be avoided. Older people are particularly at risk. As a response to this problem, The Pharmacy Guild of Australia has developed the [Home Medicines Review \(HMR\) Program](#).

### What's involved in a Home Medicines Review (HMR)?

An HMR involves your GP and a community pharmacist of your choice. Your GP sets up the review by writing a referral to the pharmacist. A pharmacist conducts an interview, preferably in the comfort of your own home, and then writes a report back to the GP. The GP will discuss any

recommendations with you and may make appropriate changes to your medication regimen. The solutions may involve:

- showing you how to take your medicines correctly
- explaining why and when to take them
- explaining where they should be stored
- what to expect when taking them
- what problems you should report to the GP
- checking that prescription medicines, over-the-counter medicines and vitamins are appropriate to take together
- clarifying any confusion with generic medicines
- giving you some help so you can remember to take your medicines
- changing your medicines.

### Who should have an HMR?

HMRs are particularly useful for people who:

- take more than five medicines a day
- have recently spent time in hospital
- are concerned about their medicines
- are confused about their

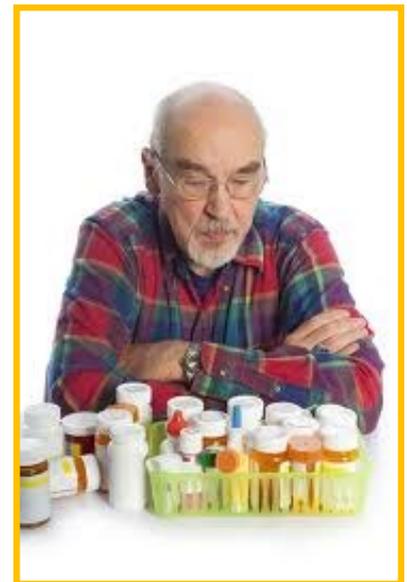
medicines

- do not always remember to take their medicines.

### How much does it cost?

The pharmacist's review and report is paid for by the Australian government, so it will not cost you anything. Your GP may bulk-bill or charge you for the GP consultations.

If you (or someone you care for) might benefit from having an HMR, talk to your GP or pharmacist about organising one. HMRs are available in all states and territories. ●



## LinC

Unemployment, redundancies, forced early retirements, a greater demand on state and federal funding in the human services areas underline the urgent need for increased involvement of churches in their local communities. LinC believes the church has all the resources and gifts needed to make a difference in local communities.

LinC mobilises the untapped potential of church people to serve with a view to empowering people to develop personal skills of self-reliance. LinC works in conjunction with human services agencies and offers assistance to all people regardless of belief, gender, race or ethnic background.

Each [LinC affiliate](#) provides services appropriate to the needs of their community and the skills of their volunteers. Some of these are:

- Driving clients to medical appointments; to exercise classes; other activities.
- Providing short term assistance in the home, maybe following an accident or injury.
- Assistance with home repairs; gardening; mowing.
- Providing food parcels
- Assistance with budgeting.
- Family support following a multiple birth; severe illness of a parent. ●

## Feature: Polio Network Members of Polio Australia

**Polio Australia is the peak, national body representing polio survivors in Australia. The Committee of Management is made up of two representatives from each of the original six state polio networks.**

**Starting with this edition, *Polio Oz News* will feature one of those networks in each edition, the first being the Post Polio Network - Tasmania Inc., now sadly disbanded. The following article was written by past-Secretary Arthur Dobson.**

This organisation was formed in May 1998 by polio survivors for polio survivors and was modeled on the Post - Polio Network (NSW) Inc. which had been formed nine years earlier.

There had previously been an organisation known as TAS POLIO SUPPORT operating in Tasmania which unfortunately was wound up when its founder, the late Bill Sullivan, could not continue for health reasons and no one else was prepared to shoulder the responsibility and workload of running it.

Our membership quickly grew to around the 110 to 120 mark with inquiries bringing just enough new members to replace those who pass away or leave for other reasons. Three Support Groups meet regularly on an informal basis. The main method of communication is however by our 40 page newsletter, TAS POLIO NEWS, which incorporates the National Polio Oz News.

Having no designated specialist services for polio survivors in Tasmania, we have been encouraging our members to take advantage of Dr Stephen de Graaff's generous offer to see Tasmanians at his Melbourne clinic. A number of our members have made the trip to see Stephen and all have come back in a much more positive frame of mind as a result of being able to talk one on one with a doctor who does understand the problems they are experiencing.

We had a very successful meeting in 2003 with the State Chief Health Officer who was principal adviser to the Minister. He was very sympathetic to our situation and knows the problems of dealing with the old school medical professionals. He told us that we have every right to refuse any treatment or medication that we believe may cause us problems and that we must encourage our members to be more assertive and demand that they be listened to and that we should wherever possible provide written information to back up our claims. We therefore promoted the Queensland Health website and the paper "[The Late Effects of Polio - Information for General Practitioners](#)" as the best source of information to start from.

It is becoming increasingly obvious that the pharmaceutical industry has a lot to answer for in releasing drugs on to the market before proper testing has taken place and we know that no testing is ever carried out on people with disabilities or who are suffering from various chronic conditions. If we can prevent polio survivors from taking inappropriate medication many of our problems would be overcome.

Polio Network Victoria has produced an outstanding video "Post Polio Syndrome - The Australian Experience" and has made it available to us. Every member of our network was contacted and everyone who could viewed the DVD or VHS tape with many also purchasing a copy. A copy of this DVD has been purchased by the University of Tasmania, School of Medicine, Clinical School which operates from the Launceston General Hospital. A number of General Practitioners have also purchased or borrowed the DVD.

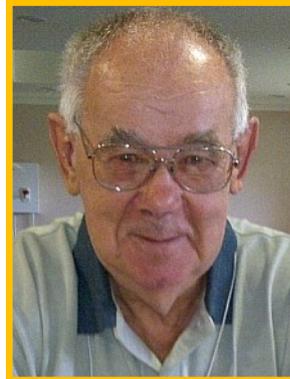
The 25th June 2007 will be a date for us all to remember, for this was the day the Tasmanian Department of Health and Human Services acknowledged our existence by holding a Public Forum on the Late Effects of Polio/Post Polio Syndrome with Dr Stephen de Graaff at the Rehabilitation Centre in Hobart. In the morning Stephen addressed approximately 45 health professionals where he spoke in a language relevant to them. The afternoon Public Forum was presented in a language more related to us polio survivors. Approximately 55 people from as far away as Wynyard, Strahan and Legerwood made the journey to hear this inspiring speaker whose knowledge of the problems we experience is unsurpassed.

It was a real eye-opener for Kathy O'Dea, the State Manager, Community Assessment & Care Management, with the DHHS who was very impressed with knowledge we already had about our condition and the help we need to live with it.

**Cont'd P 12**

## Polio Network Members of Polio Australia (Cont'd)

Chairperson Billie Thow and Secretary were actively involved in the formation of the national body Polio Australia and are on its Committee of Management. This body is now the principal reference point for Tasmania's Polio Survivors as the Post Polio Network - Tasmania was wound up in December, 2012 because of the lack of personnel to administer it after the secretary, Arthur Dobson, had to resign for health reasons. ●



Arthur Dobson



Billie Thow

## Scientists Create New Strain of Polio Virus

### Scientists create new strain of polio to protect vaccine factory workers

**Original Source:** [kaiserhealthnews.org](http://kaiserhealthnews.org) and reprinted in [News-Medical.Net](http://News-Medical.Net) - 20 February, 2013

"Scientists have created new strains of [polio](#) intended to protect workers in factories that make polio [vaccine](#)," the [New York Times](#) reports. "The new strains have the same ability to invoke an immune reaction as the live [viruses](#) now used to make vaccine do, but there is virtually no risk anyone will get polio if one of the new strains somehow escapes," the newspaper notes, adding, "The research team, at the State University of New York at Stonybrook, is led by Eckard A. F. Wimmer, a molecular geneticist who made headlines in 1991 when he synthesized polio [virus](#) in the lab from its chemical components, the first time a virus had been made outside of living cells."

"Currently, factories making the injectable Salk vaccine used in the United States and Europe start with the dangerous wild-type viruses known as Types 1, 2 and 3," the New York Times notes. "After growing a large batch, vaccine makers 'kill' the virus with formaldehyde and prepare it for syringes," the newspaper writes, adding, "The finished product is safe, but if the growing live viruses ever escaped 'because of a leak, an explosion, an earthquake, a tsunami, a flood,' Dr. Wimmer said, 'the spill could spread like wildfire.'" (McNeil, 2/18).

Read article from News-Medical.Net [here](#). ●

## Daily Living Expo

In 2013, ATSA (Assistive Technology Suppliers Australasia) will hold a Daily Living Expo in **Sydney** (Rosehill Gardens Racecourse, Rosehill, Sydney on 15-16 May 2013) and for the first time in **Brisbane** (Sheldon Conference & Entertainment Centre, Redlands, Brisbane on 23 May 2013).

In Sydney, the exhibition will have over 100 exhibitors displaying a wide range of products and services for

people with disabilities and the elderly. On display will be the latest in assistive technology, mobility solutions, pressure care, employment support, accessible recreation/holiday ideas, modified motor vehicles and a lot more.

A key feature of the Expo is the FREE Clinical Education Program - run over 2 days in rooms conveniently located above the exhibition floor. The three track seminar program has over 20 speakers.

In Brisbane, the one day event will have over 50 exhibitors, as well as an extensive one day seminar program.

Admission is free to therapists, the general public, end users & ATSA members for both events. ●

**For all Expo information, visit ATSA's website [here](#).**

## Public Transport Discrimination

### Court finds direct discrimination by Murrays Australia

Source: [Public Interest Advocacy Centre](#) Website - 14 March 2013

The Federal Court today ruled on wheelchair user Julia Haraksin's three-year battle to have bus company Murrays Australia comply with national Disability Standards.

Justice Nicholas found Murrays Australia had directly discriminated against Ms Haraksin when the bus company refused to accept a booking from her because none of its buses were wheelchair accessible.

Justice Nicholas also said Murrays Australia had breached the Disability Standards.

The Public Interest Advocacy Centre (PIAC) represented Ms Haraksin in her action against Murrays Australia.

"Today's decision puts all public transport operators in Australia on notice," said PIAC Principal Solicitor, Alexis Goodstone.

"Public transport operators



cannot afford to ignore the Disability Standards. They have a legal obligation to comply, and people with disability who are sick of being treated like second class citizens will hold them to account," Ms Goodstone said.

PIAC has been advocating for accessible public transport for people with disability for several years, acting in cases against Virgin Airlines, the NSW Department of Transport and two large taxi companies, and most recently, RailCorp.

In Haraksin v Murrays Australia, PIAC claimed Murrays breached national Disability Standards for

Accessible Public Transport when it refused Ms Haraksin's booking in 2009.

The Disability Standards came into effect in 2002. They require all new public transport vehicles to be wheelchair accessible and required 25% of transport operator's existing fleet to be accessible by 2007.

"This decision reinforces a very basic principle: everyone has a right to equal access to public transport," Ms Goodstone said. "People with disability should not have to go to court in order to catch a bus."



**SNAP!**

This photo (left) was taken in Cairns in February 2013 by polio survivor, Joy Hay.

**Thank you Rotary!**

## All about Polio Eradication

For anyone who didn't see Ewan McGregor's "*Cold Chain Mission*" on SBS One recently, you have until 20 March 2013 to watch it online [here](#).



### Summary:

The Congo - Ewan McGregor is on a mission to immunise some of the hardest-to-reach children in the world. However, the fragile nature of the vaccines means they must be kept constantly cold as they are passed along the supply chain. In the final episode, Ewan journeys up the mighty Congo River, where he passes through frontier towns in the wilds of Central Africa, encounters a unique subculture for whom style is a religion, and ventures deep into the jungle in search of Pygmy tribes. (From the UK) (Documentary Series) (Part 2 of 2) PG CC

## Dream of a Better Future for all Children

by Akram Azimi

Source: [The Sydney Morning Herald](#) - March 12, 2013

We are closer than ever to wiping out Polio - largely because of international aid, writes the Young Australian of the Year.

Imagine a world where the arbitrary location of your birth does not determine your health and educational opportunities. I dream of this world for a generation not yet born because I do not want them to grow up as I did, in the bleak reality of Kabul and Peshawar, far removed from the comparative serenity of Australia.

I can still recollect walking down the dusty cobbled streets in Peshawar, seeing children my age with wasted limbs, crawling along the ground using cut-up pieces of tires and sandals to pad their knees and hands. Curious, I asked my mother, what

happened to these children? She responded with one quietly spoken word: Polio.

"*Could I catch this disease? Would I end up begging on the streets alongside these other children?*" I asked. In her warm embrace she told me: no, you are protected. Luckily for me, I had received the polio vaccine - a vaccine partly procured with Australian aid dollars.

But those images have stuck with me, serving as a stark reminder of what my life could have been like, but for international aid. So I ask you dear reader: Is there anything more than the blind chance of birth that separates me, and indeed you, from those children left without hope on the streets of Peshawar? I think not, because no one has ever chosen the circumstances of their birth.

It is this inequity that our international aid addresses - it provides health and educational opportunities for

those who may otherwise not receive such chances.

The Australian government currently gives 35 cents out of every \$100 of national income to overseas aid. That's not much, and although many may question the effectiveness of aid, when strategically directed it achieves results. I am living proof of this.

In gratitude for all that Australia has given me, I want to give back by nurturing my fellow young Australians to dream of a different future for ourselves and our children - a future where all children have access to healthcare and education irrespective of where they are born.

That's why this week I will join 1000 young Australian leaders in our nation's capital to highlight the life-saving impact of international aid. As part of the Road trip to End Poverty, these young leaders will speak to communities in metropolitan and regional

## Dream of a Better Future for all Children (Cont'd)

Australia about how together we can help end extreme poverty, ahead of meetings with our national leaders.

The message is simple. Good aid works. Last year alone Australian aid saved at least 200,000 lives and put more than half a million children in school around the world.

We've been no less generous when it comes to ending polio. At CHOGM 2011, the Australian government announced a four-year, \$50 million commitment to the global polio eradication effort. This milestone achievement was a result of the cumulative efforts of thousands of Rotarians and ordinary Australians who believe a life free from the threat of polio is a right not a privilege.

And it has paid off. Australian support has proved to be a real game-changer in global polio eradication efforts. Our contribution has ensured that millions of children receive the

protection of the polio vaccine, and our leadership has helped convince other nations that polio eradication is worthy of action at the highest levels of government.

As a result, we are now seeing the fewest polio cases in the fewest countries in history. We're getting so close, reducing polio by more than 99 per cent and halving the number of people living on less than \$2 a day. Our aid dollars are having a real impact, and that's something worth celebrating.

This coming federal election is the last before the deadline for the Millennium Development Goals is reached in 2015. Therefore, I want to use my time as Young Australian of the Year to draw attention to the incredible progress we've made so far and how together we can end extreme poverty within our lifetime.

I look forward to the day that I can stand side-by-side with

other young leaders in front of the world stage and say: We did it, together we eradicated extreme poverty and put an end to debilitating diseases like polio.

**Akram Azimi** (pictured below) is the Young Australian of the Year 2013.

Read full article [here](#).



## WHO, Islamic Leaders Summit to Stop Polio Attacks

by James Grubel

Source: Reuters / [Chicago Tribune](#)  
28 February, 2013

CANBERRA (Reuters) - Top World Health Organisation officials and Islamic leaders will meet in Egypt next week in an effort to stop attacks on polio workers which are hampering the eradication of the virus in some countries with large Muslim populations.

*"Shooting health workers who are protecting kids from this crippling disease is against the Koran and everything Islam stands for,"* WHO's Assistant Director-General Bruce Aylward told Reuters in Canberra on Friday.

Gunmen in Pakistan and Nigeria have killed more than 20 health workers in the past three months in a series of attacks linked to a backlash against the immunization program

against the crippling virus.

*"Muslim leaders have been great advocates of immunization and generally the support has always been there. In Cairo, we are meeting senior Islamic leaders to get a sense of what we can do, and ask them how can you help us,"* said Aylward.

The WHO has successfully eliminated polio from most nations after a 25-year campaign, but the crippling condition remains endemic in three nations, Afghanistan, Pakistan and Nigeria, where some influential Muslim leaders have opposed the program as a conspiracy of western medicine.

WHO remains on target to eradicate polio globally by 2018, Aylward said, despite a violent backlash from militant groups in Pakistan and Nigeria.

## WHO, Islamic Leaders Summit (Cont'd)

But there are also worrying signs of persistence, with the polio virus found in sewers in Cairo in January, with the type linked to the indigenous strain in Pakistan. Egypt has not had a case of polio since 2004.

Aylward said the violence has forced the WHO to revise its approach to immunizations in both Pakistan and Nigeria.

*"The goal is to put tools in the hands of the communities to immunize their own kids,"* Aylward said.

*"The overall risks (of contracting polio) are getting smaller, because we are finally getting into some of these difficult places,"* he said.

Since 1988, the WHO has cut the number of global polio cases from 350,000 to just 225 in 2012, with India declared polio free in January 2012. ●



Bruce Aylward

## Islamic Scholars Call for Urgent Action on Eradication

**Source:** [Polio Eradication Website](#)

Cairo, 7 March 2013 – The Grand Imam of Al-Azhar, Doctor Ahmad Al Tayyeb, today called for the protection of Muslim children against poliovirus transmission by ensuring they receive the required polio vaccine. He stressed the importance of increasing the awareness of the correct Islamic teachings on the subject to combat all deformed and false beliefs, and confirmed that Al-Azhar is ready to continue to exert all efforts to enlighten Muslim individuals and communities about the rights of children to be protected against polio and all other diseases and the obligation of all Muslims to ensure that their children are protected. *"Crippled children lead to a crippled Muslim Ummah"* Dr Al-Tayyeb warned.

This was announced today at

a meeting held at Al-Azhar during which the Grand Imam met with Muslim scholars from several countries. The scholars expressed their solidarity with the children of the Islamic world and reaffirmed their resolve to support the people, health workers and governments of the three countries where polio is not yet eradicated, namely Afghanistan, Nigeria and Pakistan.

The Global Polio Eradication Initiative, launched in 1988 by the health ministers of the Member States of the World Health Organization, has been successful in stopping the transmission of this crippling disease in all but these three countries of the world. Except for in Afghanistan, Nigeria and Pakistan, Muslim communities and countries everywhere have eradicated polio, including 54 out of 57 member states of the

Organization of Islamic Cooperation (OIC) that have successfully interrupted transmission of wild poliovirus. This has been achieved through the application of proven eradication strategies, the administration of the safe oral polio vaccine and with financial and political support from the Islamic world.

Recognizing with grave concern the ongoing transmission of wild poliovirus in parts of Afghanistan, Nigeria and Pakistan, and the remaining political, cultural, societal and security challenges preventing all children in these areas from being vaccinated against polio, and in particular the tragic and deadly attacks against frontline health workers in parts of Pakistan and Nigeria in the past three months, Islamic scholars from several countries are meeting for two days in Cairo from 6–7

## Call for Urgent Action on Eradication (Cont'd)

March to discuss the major obstacles preventing these countries from stopping polio transmission and trying to reach a consensus on how the Islamic leadership can help Muslim communities to overcome these barriers and ensure protection for all Muslim children. 🌐

**Photo:** Grand Imam of Al-Azhar receiving Muslim Scholars to discuss children rights to be protected by vaccination by WHO/EMRO



## Polio This Week

Source: [Polio Global Eradication Initiative](#) - as of Wednesday 12 March 2013

### Wild Poliovirus (WPV) Cases

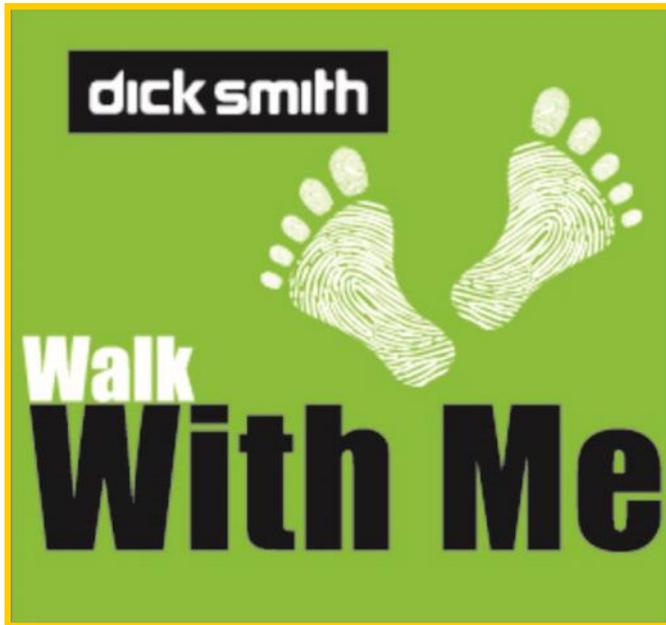
Total cases	Year-to-date 2013	Year-to-date 2012	Total in 2012
Globally	10	25	223
- in endemic countries	10	24	217
- in non-endemic countries	0	1	6

### Case Breakdown by Country

Countries	Year-to-date 2013				Year-to-date 2012				Total in 2012	Date of most recent case
	WPV	WPV3	W1W3	Total	WPV1	WPV3	W1W3	Total		
Pakistan	5			5	12		1	13	58	12-Feb-13
Afghanistan	1			1	5			5	37	31-Jan-13
Nigeria	4			4	5	1		6	122	31-Jan-13
Chad					1			1	5	14-Jun-12
Niger									1	15-Nov-12
<b>Total</b>	<b>10</b>	<b>0</b>	<b>0</b>	<b>10</b>	<b>23</b>	<b>1</b>	<b>1</b>	<b>25</b>	<b>223</b>	
<b>Total in endemic countries</b>	<b>10</b>	<b>0</b>	<b>0</b>	<b>10</b>	<b>22</b>	<b>1</b>	<b>1</b>	<b>24</b>	<b>217</b>	
<b>Total outbreak</b>	<b>0</b>	<b>0</b>	<b>0</b>	<b>0</b>	<b>1</b>	<b>0</b>	<b>0</b>	<b>1</b>	<b>6</b>	

Data in WHO as of 14 March 2012 for 2012 data and 12 March 2013 for 2013 data.

**Walk With Me 2013**



**Polio** Australia is, once again, delighted to be partnering with Scope for the [Walk With Me Melbourne](#) on Sunday 1st September 2013 (*Fathers Day*), and with Northcott for the [Walk With Me Sydney](#) on Friday 13th September 2013.

Last year, we only had 2 'walkers' - John Tierney and Fran Henke - who still managed to raise \$3,770 between them! (*pictured below*)

**The difference we can make together**

Funds raised for Walk With Me will be used by Polio Australia to pay for much needed program development including annual Polio Health and Wellness Retreats, regular polio-related publications, Clinical Practice Modules, community education, and systemic advocacy.

**Walk With Me 2013**

Walk With Me is a national walk that celebrates the achievements of people with a disability. The event will foster awareness and inclusion while raising much needed funds for organisations that support people with a disability across Australia.

Walk With Me is not a fun run, nor a competitive fitness event but a recreational walk. It provides family, friends, colleagues, businesses and members of the general public with the opportunity to make a difference in the lives of people with a disability.

So take the challenge, choose an event in your area and Walk With Me!

**How to get involved**

- **Join our walk** - register to get involved with this inclusive community activity
- **Sponsor a walker!** - choose who you would like to support - donations are tax deductible and can be made online.

Simply go to [Polio Australia's Walk With Me](#) web page and follow the prompts. And keep checking the webpage for updates leading up to the events.

**Melbourne**

When: Sunday 1st September  
 Where: Birrarung Marr, Melbourne  
 On the Day Registration: 9.00am  
 Pre-registration check in: from 10.00am  
 Pre Walk Warm Up: 10.45am  
 Walk Starts: 11.00am  
 Entertainment: 11.30am - 1.00pm  
 Event Concludes: 1pm  
 Tickets: \$50 family, \$25 adult, \$10 concession

**Sydney**

When: Friday 13th September  
 Where: Banks of Parramatta River (between Barry Wilde Bridge and Rivercat Wharf Parramatta)  
 On the Day Registration: 11.30am  
 Walk Starts: 12.30pm  
 Entertainment: 11.30am - 2.00pm  
 Tickets: Free

For further details, email: [office@polioaustralia.org.au](mailto:office@polioaustralia.org.au)

- Ed

Dr John Tierney at the 2012 Walk With Me event in Melbourne



Fran Henke at the 2012 Walk With Me event - completed in Hastings