

**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 contracted 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 bulbo-spinal 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 bulbo-spinal 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.

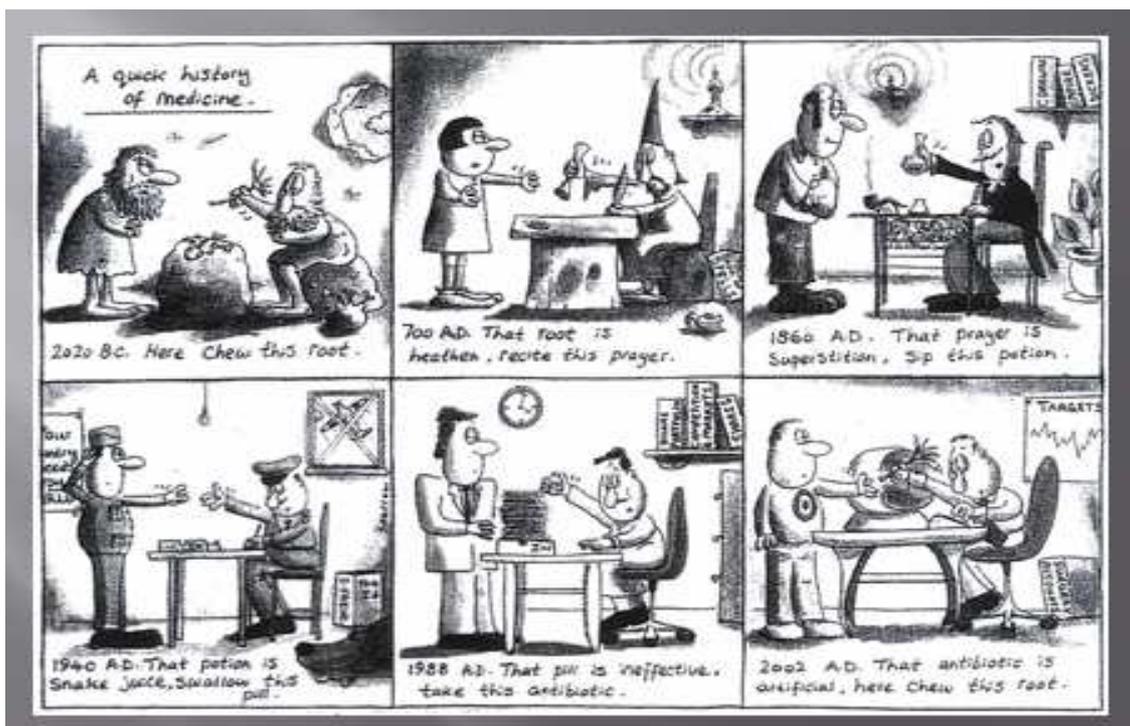
This was a partial help, but none of these references pointed to any reasons for polio to impact the bladder muscles. The only two published medical articles I could find were references in the *Journal of the American Medical Association* in 1948 and the *Journal of Urology* in 1936.

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 unlearned), 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. At the top left is the logo, which consists of a stylized white figure with arms raised inside a circle, with a small red heart above it. To the right of the logo, the text reads "Independent Living Centre NSW" in a white serif font, and below that, in a smaller white sans-serif font, "Changing Lives Through Assistive Technology". Below the logo and text are four rows of contact information, each preceded by a small 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 of the graphic is a 3D illustration of several stylized human figures in white and blue, holding hands in a circle.



# 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

Gillian Thomas	President	president@polionsw.org.au	02 9663 2402
Susan Ellis	Vice-President	vicepres@polionsw.org.au	02 9487 3094
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

<b>Office staff:</b> George, Carlie and Fatma		office@polionsw.org.au	02 9890 0946
<b>Volunteers:</b> Nola and John			02 9890 0953
Susan Ellis	Seminar Co-ordinator	seminar@polionsw.org.au	02 9487 3094
Alan Cameron	Website Webmaster	webmaster@polionsw.org.au	0407 404 641
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.