



# POST - POLIO NETWORK (NSW) INC.

## NETWORK NEWS

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### President's Corner

Gillian Thomas

Welcome to new members and regular readers. I hope you enjoy this issue of *Network News*. Unfortunately, the promised article on Osteoporosis (resulting from our November 2007 Seminar) has not yet been received. I will continue to follow this up with a view to publishing it in the next *Network News*.

On **page 2** you will find full details of our **Seminar** to be held on **Saturday 14 June** at **Ryde-Eastwood Leagues Club**. **Craig Knox** will be speaking about **Orthopaedic Surgery Recovery and the Polio Patient** in a encore of the talk he gave members in Ballina last September. If you are planning a joint replacement or other orthopaedic surgery, this is one presentation you won't want to miss. Craig is travelling from Lismore to present this topic so we hope members will turn out in force to hear what he has to tell us.

It will shortly be **Membership Renewal** time. Enclosed, you will find one of two forms, depending on your financial status. If you are currently paid up to 30 June 2008 (your address sheet reads **Renewal Due On: 1/07/08**) you will find a **Membership Renewal Form** enclosed for the period **1 July 2008 to 30 June 2009**. **Could you please confirm, complete, or amend your details as given on the Form, and return it with your subscription to the Treasurer at the Network's Parramatta postal address**. Quite a number of members appreciate the ability to pay their membership subscription via **internet banking**. If you take up this option, please **ensure your name is recorded on the payment and email the payment transaction details to <treasurer@post-polionetwork.org.au>**. Without this information it may be impossible for us to credit the payment to your membership. Also, if you post in your payment, please be sure to **return the entire Renewal Form** with your subscription – **please don't tear off and return only part of it**.

There is still a considerable number of people whose annual subscriptions are overdue, and so their address sheet reads **Renewal Due On: 1/07/07 (or earlier)**. In this case, the **Membership Renewal Form covers more than one year's membership**. We would appreciate prompt payment of the outstanding dues, together with the current dues, to ensure that you continue to receive *Network News*.

**The Network is self-funded and needs your continued support to enable us to keep providing services to polio survivors and their families.**

**If you are already financial beyond 30 June 2009** (as shown on your address sheet), you will receive a **Membership Update Form** which gives your current details but does not request payment of a membership subscription. **Please check your details and be sure to return the Form if any amendments are required.**

Regular readers will recall that **Dr Lauro Halstead** (Director, Post-Polio Program, National Rehabilitation Hospital, Washington) was invited by the Network to come to Australia in 2001 and give a series of presentations on his work. Mary-ann Liethof from Polio Network Victoria recently met with Dr Halstead while on her Churchill Fellowship Study Tour to the USA and Canada (see *pages 4 to 7*). Dr Halstead's Australian trip was cancelled because, as Mary-ann writes, "9/11 laid to rest any imminent travel plans for the family. Hopefully, these plans can be resurrected – perhaps via "Polio Australia" – some time in the not-too-distant future. It would be an exciting opportunity to hear from such a respected leader in the field of Post-Polio. His wife, Jessica Scheer, a Research Professor at the Department of Prevention and Community Health, is also well versed in working with polio survivors, with a wealth of information to share on the subject herself." If funding can be arranged, this is certainly something that it would be appropriate for Polio Australia to consider.

Finally, from the next issue of *Network News* we are planning a couple of new regular features, **Members' Stories**, and a page of **Helpful Resources** which will be compiled and regularly updated by our Office. If you have anything to contribute to either initiative, we would love to hear from you. Until next time!

Unless otherwise stated, the articles in this Newsletter may be reprinted provided that they are reproduced in full (including any references) and the author, the source and the Post-Polio Network (NSW) Inc are acknowledged in full. Articles may not be edited or summarised without the prior written approval of the Network. The views expressed in this publication are not necessarily those of the Network, and any products, services or treatments described are not necessarily endorsed or recommended by the Network.

# Orthopaedic Surgery Recovery and the Polio Patient

**Date:** Saturday, 14 June 2008

**Time:** 1:00 pm – 4:00 pm

**Venue:** Willandra Room  
Ryde-Eastwood Leagues Club  
117 Ryedale Road, West Ryde  
*For location information, visit <[www.releagues.com.au](http://www.releagues.com.au)>*

**Lunch:** Bringing your own lunch is not an option at this venue  
Light lunches are available from the *Palm Court Bistro* (around \$10.00)  
*The Coffee Club* has gourmet sandwiches, snacks and treats

**Afternoon Tea:** Courtesy of the Network – ***please RSVP by Tuesday 10 June***

Our guest speaker, Craig Knox, is a Physiotherapist at Lismore Base Hospital. Craig gave an excellent presentation on this topic to those attending our Ballina Conference last September. The Management Committee wished to make his knowledge more widely available to members and so invited him to present this metropolitan Seminar.

Craig attended Cumberland College of Health Sciences (now part of Sydney University) in Lidcombe to study Physiotherapy. After graduating in 1992, he worked in and around Wollongong, and the south coast, before travelling and working in the UK for 2 years. On return, he discovered the North Coast of NSW and has been there ever since.

From 1996 to 2002, Craig worked in a combination of private and public outpatient services, treating mainly sore backs/knees/shoulders as well as post-surgical patients. Not once did he encounter an obviously polio-affected patient, which he feels reflects the under-utilisation of health resources by polio survivors. Craig wonders whether the “*she’ll be right*” attitude precludes this access, or whether many polio survivors just don’t disclose they have had polio?

In 2002, Craig took over as the *Orthopaedic Care Co-ordinator for Joint Replacements* at Lismore Base Hospital, in between fathering two children. Since that time he has seen some 1,400 joint replacements – on people aged from 17 through to 97 – males and females, because of rheumatoid arthritis and osteoarthritis, as well as trauma. However, over this period he has only seen two joint replacements in people affected by polio. Since he spoke at Ballina, he has been made aware of more polio patients that he saw who didn’t identify themselves as polio survivors during their hospitalisation. Only since he has mentioned his talk at our Conference have they offered this new information. In hindsight, Craig believes he probably could have treated them quite differently if he had known, which is why it is important to tell him.

Craig firmly believes that there are variations in the way that polio and non-polio patients should be treated, both before and following a joint replacement. His presentation aims to inform us, so that we as individuals can help ourselves in deciding whether a joint replacement is appropriate for us, and if so, what could be some of the pitfalls in recovering from such surgery.

As usual, this will be an interactive session with plenty of time available for questions.

*In order to ensure that Afternoon Tea is sufficiently catered, you are requested to telephone our Office on 9890 0946 or email <[office@post-polionetwork.org.au](mailto:office@post-polionetwork.org.au)> to confirm your attendance.*

***Final numbers for Afternoon Tea must be advised to the Club prior to the Seminar, so please get in touch with our Office team by Tuesday 10 June to confirm you are coming.***

*We look forward to seeing everyone there and hope that the move to Ryde for this event will make it easier for some of you to get to a Seminar. If this will be the first Seminar you have attended, please be sure to introduce yourself to a Committee member.*

# Get on the Red Carpet !



**June is the Month of Film so get your friends, families and carers ready...**

The Sydney Film Festival, in partnership with **Accessible Arts NSW**, has launched the much-anticipated films included in the **Accessible Cinema** strand this year. Following the success of last year's program, Clare Stewart, Executive Director of the Sydney Film Festival, promises an outstanding selection of films by or about people with disabilities. These range from first screenings of Australian disability films to international films that will inspire, fascinate and connect all film-goers.

Building on the success of last years program, Accessible Arts is thrilled to be involved in what is to be a powerful collection of films, and, for the first time, a forum entitled **Silence is Golden** will give people the opportunity to discuss and debate the future of accessible cinema.

*"The Sydney Film Festival has highlighted once again that they are able to broaden the scope of their program and provide strong links with the disability sector in Australia and around the world. This takes us a huge step forward in actively engaging all people in the arts."* Sancha Donald, CEO, Accessible Arts.

**The 55<sup>th</sup> Sydney Film Festival will run from 4 to 22 June 2008**

To view the Accessible Cinema program and venue access information, visit [www.sydneyfilmfestival.org](http://www.sydneyfilmfestival.org) and go to the **Accessible Cinema** link on the program page.

## **TICKETS**

Tickets and Flexipass are available for purchase on the Sydney Film Festival website. Select the movie you are interested in and click "Buy Tickets" or you can contact Ticketmaster via phone on 136 100.

For specific access requirements in order to purchase your tickets, such as booking an audio description head set or a wheelchair accessible seat, please contact the Sydney Film Festival for further information via phone - 02 9318 0999, fax - 02 9319 0055 or email - [info@sydneyfilmfestival.org](mailto:info@sydneyfilmfestival.org).

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## **About Accessible Arts**

**Accessible Arts is the peak arts and disability organisation across New South Wales.** Accessible Arts promotes and provides opportunities for people with disabilities to participate in arts and cultural activities either as audience members; through attending galleries, theatres, museums and festivals; or as participants in art, drama, music, dance and multimedia activities; and by developing as professional artists. Over the years Accessible Arts has worked in assisting arts organisations such as Sydney Opera House, Sydney Art Fair, Biennale of Sydney and Sydney Film Festival. To keep up to date with upcoming news and arts events subscribe to the free Accessible Arts monthly newsletter at [www.aarts.net.au](http://www.aarts.net.au).

# Towards the Better Management of the Late Effects of Polio

In July 2007 Mary-ann Liethof, Polio Community Officer, Polio Network Victoria, was honoured and delighted to be awarded a Churchill Fellowship to undertake a Study Tour of the USA and Canada during April and May 2008. Her project is “*To identify techniques to better manage the late effects of polio*”.

On her return to Australia, Mary-ann will be conducting a series of presentations on her Study Tour findings. She will be travelling throughout Victoria this coming October. As foreshadowed in the last *Network News*, we have arranged for her to also come to Sydney to present our AGM Seminar on 22 November. About the Study Tour she writes:

*As we know, Australia has virtually been polio-free since the early 1960's, so the majority of Australian-born survivors tend to be an ageing population. Unfortunately, this factor is also contributing to disability levels. The number of polio survivors seeking information and support is actually on the increase with at least 100 new enquiries per year in Victoria alone. This demand will be continued in years to come from younger migrants who contracted polio in countries where polio has only recently been eradicated, or where outbreaks are still occurring. This is already evident at Polio Services Victoria with the average age of people requesting specialist advice dropping from 69 to 51 years old in the last 4 years.*

*As Australia has limited services for polio survivors and no research currently being undertaken, the overall purpose of this Study Tour is to:*

- ❖ *identify the latest research into the cause and management of Post Polio Syndrome symptoms,*
- ❖ *observe a variety of “best practice” services for polio survivors,*
- ❖ *learn about the range of resources and equipment available,*
- ❖ *enhance understanding of the wider implication of emotional and psychological issues that impact on polio survivors and family members, and*
- ❖ *open communication with clinicians specialising in PPS and create networks and links for Australian health professionals to pursue.*

Mary-ann has been filming her interviews with those she has met and hopes these might be used to educate polio survivors, their families, health professionals and the general community. Joining Mary-ann on the Study Tour is Jill Pickering, polio survivor and long-term volunteer with Polio Network Victoria. Jill is providing invaluable, first-hand experience of the management strategies being learned as they travel from Los Angeles to St Louis, Atlanta/Warm Springs, Washington DC, Johnstown (Pennsylvania), Englewood (New Jersey), New York, Framingham (Massachusetts), and then into Canada where they will visit Toronto and Ottawa before finishing the Tour in Montreal at the end of May after an invigorating but exhausting six weeks.

Modern technology means that Mary-ann and Jill are able to quickly share their experiences on their travels by uploading diary entries and photographs to Polio Network Victoria's website using a trusty laptop computer and an internet connection from their hotel rooms. On the following pages I have given just a few glimpses of their travels and the polio experts they have interviewed. To see the full itinerary, read all the diary entries and view the many photographs you can visit <[www.polionetworkvic.asn.au/study-tour](http://www.polionetworkvic.asn.au/study-tour)>.

Don't forget to keep Saturday 22 November free to come along to our Annual General Meeting and hear Mary-ann's full report on her six-week odyssey.

# Joan Headley - St Louis - Monday 28 April 2008

**Mary-ann Liethof**



L to R Joan Headley, Jill Pickering, Mary-ann Liethof

We arrived at Post-Polio Health International (PHI) at 9:30 am where we met with the Director, Joan Headley, and Brian, a brand new staff member. I'm sure his first day proved to be as effective an orientation to PHI as it was for us. I set up the video and taped my interview with Joan as she discussed the service and the various research projects they have funded. PHI is an information resource for polio survivors, their families and the health care community. It actively promotes networking between survivors, professional communities and assistive equipment manufactures. PHI also publishes a quarterly newsletter, compiles the Post-Polio Directory which lists post-polio health resources and polio support groups around the world, and maintains a website <[www.post-polio.org](http://www.post-polio.org)> that averages 50,000 hits (visits) per month.

## Jill's Jottings

### Jill Pickering

It was very encouraging to hear how Post Polio Health International started from the dream of one very pro-active and forward thinking person [Ed. Jill is referring to Gini Laurie – you can read all about her efforts here <[www.post-polio.org/about](http://www.post-polio.org/about)>.] Amazing to see how the drive of these early founders achieved so much.

# Dr Lauro Halstead - Washington DC - Tuesday 6 May 2008

## Mary-ann Liethof

Today we were off to the National Rehabilitation Hospital to meet with Lauro S Halstead, MD, who contributed to and edited the 2nd edition of *“Managing Post-Polio: A Guide to Living and Aging Well with Post-Polio Syndrome”* printed in 2006 [Ed. copies are available through the Network] – one of many publications produced throughout his career. Dr Halstead contracted polio at the age of 18 and, as he writes in Chapter 15 of his book under *“The Lessons and Legacies of Polio”*, he *“... made the trip from iron lung to wheelchair and then to no assistive device within six months. This experience taught me a number of things, including denial. I had recovered and, although my right arm remained largely paralyzed, I did not think of myself as disabled – just inconvenienced.”* Dr Halstead went on to graduate from medical school and specialize in the area of Internal and Neuro/Rehabilitation Medicine, working primarily with people who had spinal cord injury.



Ginger Stewart Walls and Dr Lauro Halstead

With his medical background and personal experience, Dr Halstead was clearly an ideal physician to head the Post-Polio Clinic at the National Rehabilitation Hospital (NRH) in Washington DC. We met with Dr Halstead for an overview of the work he does at NRH (now part-time) before being introduced to one of his team members, Ginger Stewart Walls, a Physical Therapist and Clinic Director specialising in Neuro Rehabilitation with the Outpatient mobility clinic. Ginger offered to show us around her area including the hydrotherapy pool (34°C / 94°F), the physical therapy exercise and assessment room, the seating centre, and a brilliant facility called “Independence Square” which is a large area set up with the same services and related obstacles that need to be negotiated within the general community – all in the safety of a controlled environment. There was a supermarket with a turnstile, a bank and cafe, steps, ramps, a bedroom, bathroom and kitchen, and an excellent adaptive driving simulation. We were really impressed with this set up.

# Dr Richard Bruno - New York - Monday 12 May 2008

**Mary-ann Liethof**



Quoting from his biography, "*Dr Richard Bruno is a Clinical Psychophysicologist treating and studying mind/body problems, including chronic pain, fatigue and stress, as well as Post-Polio Sequelae (PPS)*".

Wikipedia <[www.wikipedia.org](http://www.wikipedia.org)> explains that "*While psychophysiology was a discipline off the mainstream of psychological and medical science prior to roughly the 1960 and 1970s, more recently, psychophysiology has found itself positioned at the intersection of psychological and medical science, and its popularity and importance have expanded commensurately with the realization of the inter-relatedness of mind and body.*" Many people will be aware of Dr Bruno's book, "*The Polio Paradox*" which works on this principle and has made a big difference in the lives and understanding of many polio survivors.

Dr Bruno has recently moved from a practice suite within Englewood Hospital to a modest clinic a bit further down the road. One of the reasons for this is so that patients don't feel anxious by having to enter a hospital setting in the event of previous unpleasant memories. His clinic sees 4 new patients per week, 2 "local" (up to 2 ½ hrs drive away) and 2 from everywhere else. He has treated many polio survivors from all over the world. During the initial assessment, Dr Bruno will see the patient for 1 hour, followed by other specialists including a medical doctor, physical therapist, orthotist, dietitian, occupational therapist, and orthopedist.

Dr Bruno's main focus is on assisting the patient with 'reprogramming' the habits of a lifetime from overworking/overachieving to regulating their pace to match their energy capacity.

Dr Bruno and I went on to discuss the concept that government and funding bodies have the idea that PPS will not be an issue for very much longer due to the age demographic of polio survivors. However, he provided statistics of the numbers of Americans who were still contracting polio years after the vaccine had been introduced in 1955. Population-adjusted numbers also hold true for Australia which means there are many Western polio survivors who are still only in their 40's and, therefore, have a lot more living to do. We also need to think about the people in countries where polio is still prevalent, or have only more recently become 'polio free' (how long this remains the case is in direct proportion to how scrupulously the immunization rate is kept up).

## Jill's Jottings

### Jill Pickering

I liked Dr Bruno's emphasis on the need for many Post Polio's to revisit their initial negative hospital experiences and to face their "Polio Demons" before they could come to terms with new limitations and new ways of dealing with Post Polio Sequelae (such as replacing "use it or lose it" with pacing, aids etc). Other disciplines were accessed via the nearby hospital and reports coordinated by Dr Bruno.

# Nutrition for Polio Survivors

Richard Grzegorzulka is a clinical dietician who works with *Ballina Community Health* specialising in community nutrition, school education programs and aboriginal health. He spoke on *Nutrition for Polio Survivors* at our Ballina Conference last September, emphasising the basics of good nutrition practice for healthy living. For weight loss or control, here are some of Richard's meal ideas.

## BREAKFAST IDEAS

### Simple:

- BREAD - multigrain or wholemeal is best, with scrape of margarine
- And/or
- CEREAL - wholemeal like weet bix or porridge is best
- MILK - fat reduced is best, especially if you have more during the day.
- FRUIT



### Cooked:

Can add things like:

- EGGS - add very little oil if frying
- BAKED BEANS - small can
- FISH - small fillet, add very little oil
- VEGETABLES (you can eat as many vegies as you want)

### The combination is up to you - here's some ideas:

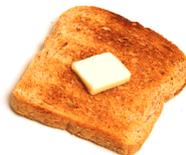
- 2 eggs – poached
- 2 toast, skip the marge
- grilled tomatoes



- 1 fresh orange
- 3 grilled fish fingers
- 1 toast, scrape of marge

- Small can baked beans
- (add onion, celery, capsicum if you want)
- 2 toast

- 2 cups of mushrooms (add a little water to cook)
- 2 Tablespoons grated cheese
- 2 toast



- Diet yoghurt
- 1 fresh fruit
- 1 egg - scrambled
- 1 toast, scrape of marge

- Small piece of fish
- Steam or fry in a little oil
- Tomato and onion cooked
- 1 toast

# LUNCH IDEAS

## SANDWICH

- Use 2 slices of bread (wholemeal or multigrain is best) OR 1 Pita bread. Make it thick with lots of salad veggies like tomato, grated carrot, cucumber and beetroot. Scrape of marge or use low fat mayonnaise.
- **Add to it:**  
1 thin slice of corned beef or ham, OR 1 hard boiled egg, OR 30g lean chicken, OR sardines/tuna, OR 1 slice of cheese
- **Add to it:**  
One piece of Fruit or 1cup tinned fruit OR Diet Yoghurt.  
You also can add a vegie or tomato soup as a “free” extra if still hungry.



## SALAD

- Use lots of Salad veggies to fill up your plate - vinegar or lemon as dressing if you want.



- **Add to it:**
  - 2 hard boiled eggs, OR small can tuna/salmon, OR 2 thin slices of cold meat,
  - OR small piece of lean chicken, OR small piece of (grilled/boiled) fish
- **Add to it:**  
1 slice of bread (or 3 crispbread biscuits), OR half a cup rice, OR 1 potato.

## COOKED LUNCH

- Use lots of cooked vegies to put on your plate or put in a stew or in a curry.
- Use only a small amount of meat (60g), chicken or fish.
- Go easy on potato, rice or pasta,  
(Remember - this is not the main meal)

### The combination is up to you - here's some ideas:

- Vegetarian mini pizza made on pita bread (tomato paste, onion, capsicum, mushroom,
- 2 Tsp cheese
- Baked or grilled

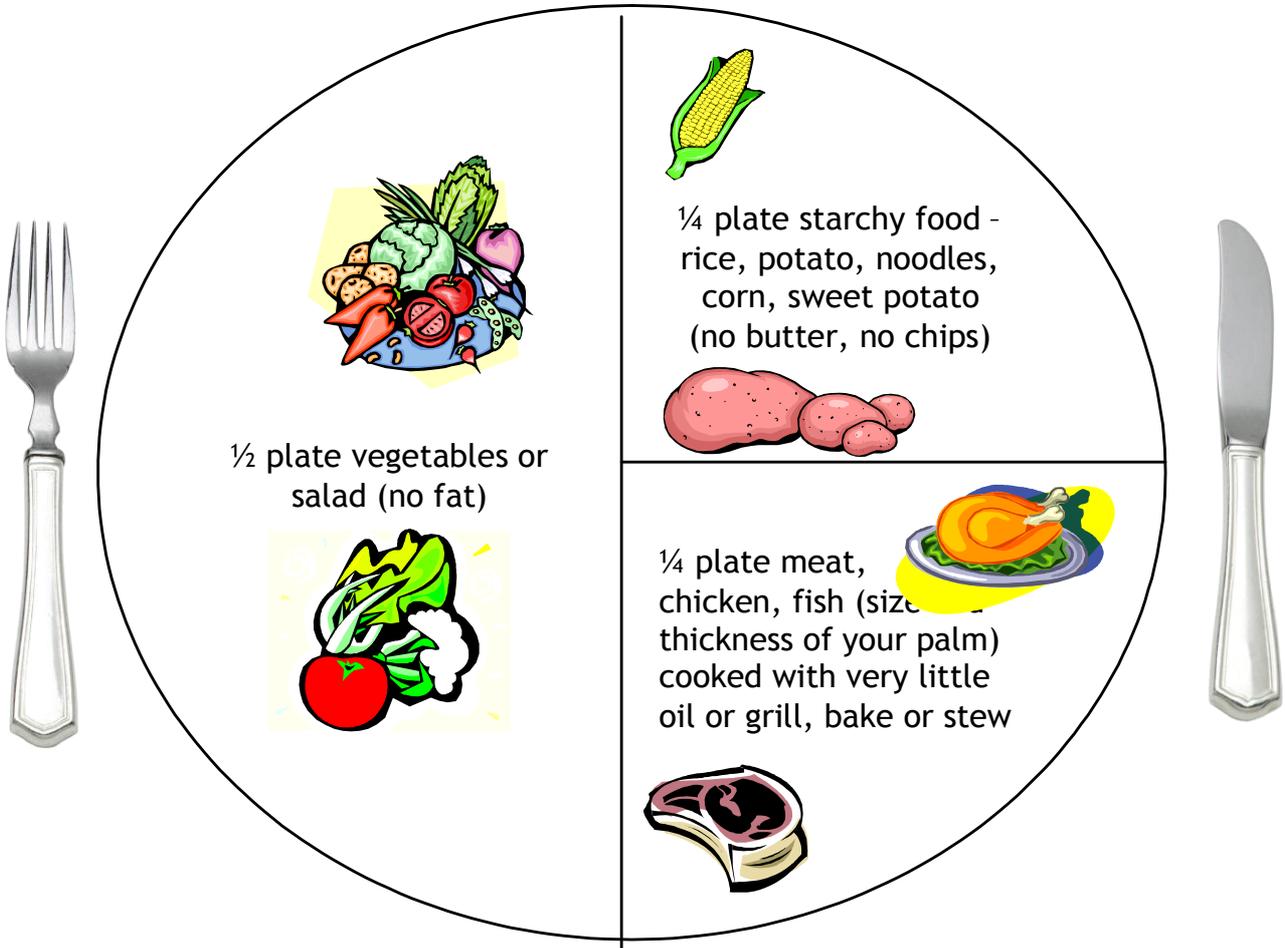
- Multigrain chicken and salad sandwich
- Vegetable soup

- 2 egg omelette with salad
- 1 toast and fruit



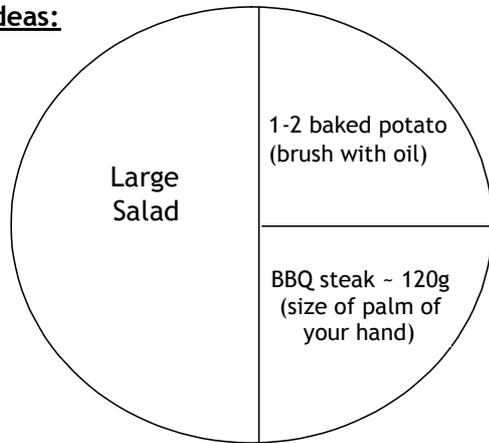
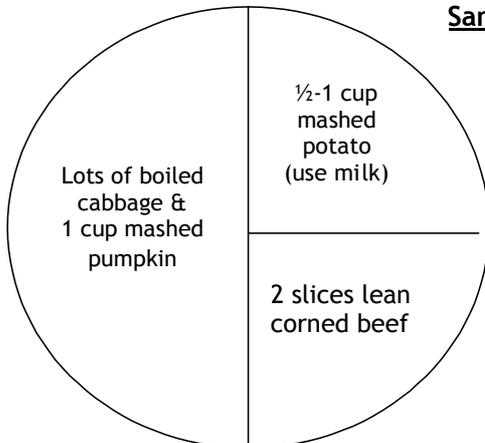
# MAIN MEAL

This is usually the biggest meal of the day - but doesn't need to be heavy or fattening.



As you can see there is more vegetables on the plate than meat or starchy foods like potato or rice. Same thing if you make a curry or a stew - make sure you add things in the same proportion (lots of vegetables, less meat and rice).

### Sample Meal Ideas:



# SNACK ATTACK

## What can you have, as much as you want ?

- ❖ **Fruits and juices** - Strawberries, passion fruit, lemons, vegetable juices, tomato juice.



- ❖ **Vegetables** - Asparagus, beans, broccoli, cabbage, capsicum, carrots, celery, choko, cucumber, eggplant, lettuce, mushrooms, onions, peas, pumpkin, spinach, tomatoes, zucchini, and things made from them like salsa dip or vegetable soup.



- ❖ **Drinks** - Water, tea/coffee, soda water, plain mineral water, diet cordials/soft drinks, vegetable soup.



- ❖ **Others** - Diet (low joule) jelly, fish/meat paste, and



Vegemite.

So, you can use these things listed to have when you are starting to get hungry - it might fill you up enough, so you can wait for the next meal.

## Need more to eat?

If you need more to eat, try and keep it to about the size of a slice of bread or some fruit. Here's some examples:-

- ❖ Use 8 rice crackers with salsa dip



- ❖ Vegetable sticks, like carrot and celery and dip into low fat yoghurt (or cottage cheese) flavoured with sweet chilli sauce (or sauce of your choice)



- ❖ 1 slice of multigrain toast with vegetable or tomato soup.

- ❖ Diet jelly set with some fruit in it - can add some low fat yoghurt to have with it.
- ❖ 2 Ryevitas or crispbreads with low fat mayonnaise and tuna or sardines and vinegar.

# Post-Polio Forum

by Richard Louis Bruno, April 2008 (excerpted from *New Mobility Magazine*)

*Dr Richard Bruno is director of The Post-Polio Institute at Englewood Hospital and Medical Center. You can email him at <postpolioinfo@aol.com>.*



*Dr Bruno writes the regular feature "Post-Polio Forum" in "New Mobility Magazine". In this extract from the April edition, he gives an update on his earlier report (re-published in Network News Issue 74) on the drug Provigil.*

December 2007's *Post-Polio Forum* described studies finding Provigil ineffective in reducing post-polio fatigue. The FDA has now warned that serious and sometimes fatal conditions have been associated with Provigil: Stevens-Johnson syndrome and toxic epidermal necrolysis (coughing, aching, headaches, chills and fever, followed by a red rash across the face and trunk that can spread and blister) puffy, swelling skin, and a sometimes fatal multiple organ damage.

Provigil also is associated with psychiatric symptoms, including anxiety, mania, hallucinations and suicidal thoughts, and caution is advised when giving Provigil to people with a history of psychosis, depression or mania. The FDA warns people to immediately stop Provigil and contact health care professionals if these symptoms occur.

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## Polio Australia - A National Voice For Polio Survivors

The Constitution, and a related *Memorandum of Understanding* (MOU) between all the State Networks, are nearing finalisation. In drafting the MOU, Polio Australia is very fortunate to have secured pro bono legal advice from a leading Australian law firm, Mallesons Stephen Jaques. The State Networks which are largely self-funded are very grateful to have received this professional assistance which they would not otherwise have had the resources to access. The formal establishment of Polio Australia should soon become a reality.

In the meantime, Polio Australia is continuing to raise its profile as opportunities arise. Here is an extract from our 500-word submission to the *2020 Summit* (to keep the word count down, LEOP = the late effects of polio):

*Many polio survivors who have emerging symptoms still report difficulty in obtaining correct diagnosis and treatment and are increasingly seeking information on managing the condition and in need of comprehensive support services. However, there is significant lack of support and understanding for people with LEOP, in all areas, including medical and therapeutic assistance, information, understanding and emotional support for people with LEOP and their carers and families. To date, support has been through state-based consumer-run volunteer organisations providing information and support to large numbers of their peers and to health professionals, generally without the benefit of any public funding. Polio Australia has now been formed and is seeking a commitment from the Government to support polio survivors through:*

- *a comprehensive education program for medical and allied health professionals around diagnosing and managing LEOP;*
- *specialist knowledge and expertise in the area gained through liaison with international experts;*
- *clinics in each state with a collaborative approach and adequate resources to manage the complex needs of people with LEOP; with input from orthotists, physiotherapists, occupational therapists, rehabilitation specialists, neurologists, social workers etc;*
- *funding for the state-based organisations to continue providing crucial and unique information and support to polio survivors.*

# Post-Polio Network Submission to 2020 Summit

*On behalf of the Network, our Vice-President Merle Thompson made the following contribution towards the Summit's deliberations on "A long-term national health strategy". Merle certainly managed to pack a lot of information into the maximum allowable 500 words!*

The Network provides information and support to people who have contracted poliomyelitis. Most have been living with its effects for 30 to 90 years.

A recent research project <sup>1</sup> outlines many of their health difficulties:

- Residual difficulties of varying severity continuing from the initial illness, often with major restrictions on their lives. Problems include partial/complete quadriplegia/paraplegia, scoliosis, shortened or withered limbs, breathing problems and the need to use aids/appliances – wheelchairs, calipers, orthopaedic shoes, crutches/sticks. Others appeared to recover completely, leading physically active lives.
- Most are now experiencing "the late effects of polio". There are 15 generally recognised symptoms with 10% of survey respondents experiencing all of these (average 9.2). Most have the debilitating problems of muscle weakness (92%) and fatigue (89%).
- A number of conditions are considered to be disproportionately more common among polio survivors, including osteoporosis, scoliosis, difficulty with weight control and hiatus hernia. Survey responses support this contention.

The cumulative effects of these conditions, often exacerbated by ageing, can result in difficulty in handling the demands of everyday life including walking, personal care and household tasks, driving and using public transport. Many are dependent on aids and appliances.

For many polio survivors it is difficult to obtain health care in which there is recognition and understanding of the conditions involved and which is coordinated to address the range of problems encountered:

- As it is over 40 years since the last epidemic in Australia, few health practitioners have seen acute polio.
- The extent of the problem is not recognised and few specialised services are available.
- Some practitioners debate definitions of Post-Polio Syndrome and the Late Effects of Polio and do not provide the required care for those not meeting their definition. Others do not accept that the conditions exist and disparagingly state that the problems are purely ageing or weight gain.

It is thought that there were between 20,000 and 40,000 cases of paralytic polio in Australia. This may only represent 2% of those who contracted the virus. It is now considered that some people who were not paralysed, or who even were asymptomatic, are now also experiencing the late effects of polio. Consequently the scope of the problem is extremely large.

In order for polio survivors to be able "to access the best possible care" the following would be desirable:

- Recognition of Post Polio Syndrome and the Late Effects of Polio by health professionals and educational programs to assist them to understand the needs of polio survivors.
- Co-ordinated health services to ensure all necessary treatments and services are provided and that treatments are not counter-productive.
- Aids and appliances at an affordable price and of a high quality to meet the needs of the person, not according to formulae or price.
- Access to health cards for those who have to retire early but are not eligible for aged or disability support pensions.

<sup>1</sup> *Polio: The living legacy* – Merle Thompson – October 2007 [Ed. Copies are available through PPM]

# Disability Treaty Closes a Gap in Protecting Human Rights



There are seven landmark United Nations human rights treaties that protect the rights of women, children, migrant workers and others, but until the **Convention on the Rights of Persons with Disabilities** entered into force on 3 May 2008, there has been no specific global treaty addressing the needs of persons with disabilities, the world's largest minority.

While many contended that existing treaties covered persons with disabilities along with everybody else, it was clear that without a legally binding treaty that spelled out their rights, persons with disabilities faced being legally "invisible" in their societies and even in the international arena. The result has been that persons with disabilities continue to face major hurdles and discriminatory practices in their daily lives.

About 650 million people in the world – or about 10 per cent of the total world population – experience various forms of disabilities, according to the World Health Organization (WHO). Eighty per cent of persons with disabilities – more than 400 million people – live in poor countries, the least equipped to address their needs. All over the world, persons with disabilities continue to face barriers in their participation in society and lower standards of living.

When immediate family members are included, the number of people affected by disabilities exceeds one billion. This is particularly important, as disabilities are a contributing factor for poverty, reduced access to education and health, exclusion and discrimination for both persons with disabilities and their families.

The purpose of the Convention, as stated in Article 1, is to *"to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity"*.

The Convention marks a major shift in the way societies view persons with disabilities, with the person being the key decision-maker in his or her own life. It makes persons with disabilities "rights holders" and "subjects of law", with full participation in formulating and implementing plans and policies affecting them.

## **Disability is a socially created problem**

The Convention moves beyond the question of access to the physical environment, to broader issues of equality and elimination of legal and social barriers to participation, social opportunities, health, education, employment and personal development.

States that ratify the Convention are legally bound to treat persons with disabilities not just as victims or members of a minority, but as subjects of the law with clearly defined rights. They will have to adapt their domestic legislation to the international standards set forth in the treaty.

The Convention promotes human rights standards and their application from a "disability perspective", promoting equal citizenship after a long history of discrimination.

The treaty views disability as a result of the interaction between an inaccessible environment and a person, rather than an inherent attribute of an individual. It replaces the old "medical model" of disability by a social and human rights model based on the fact that it is society that "disables" persons with disabilities from exercising their human rights as citizens.

This approach reflects the social perspective taken by the *International Classification of Functioning* of WHO, which sees disability as a universal human experience and not a concern of a minority: every human being can suffer from a health loss and experience some disability.

## **The Convention sets global standards on disability rights**

The global population of persons with disabilities is increasing, says WHO. Population growth, medical advances and the ageing of the world population all contribute to this increase. In countries with life expectancies over 70 years, individuals spend on average about 8 years, or 11.5 per cent of their life span, living with disabilities.

Many countries still do not have laws on disability. According to the *Inter-Parliamentary Union*, only one third of countries have anti-discrimination and other disability-specific laws. The Convention will prompt governments to create legislation or improve current laws to bring them up to the standards it sets.

The Convention has many other advantages. It provides accepted global legal standards on disability rights; clarifies the content of human rights principles and their application to the situation of persons with disabilities; provides an authoritative and global reference point for domestic laws and policies; provides effective mechanisms for monitoring, including supervision by a body of experts and reporting on implementation by governments and NGOs; provides a standard of assessment and achievement; and establishes a framework for international cooperation. It also helps to educate public opinion as countries consider ratification.

The treaty recognizes reproductive rights and is the first universal human rights treaty that mentions sexual and reproductive health. Studies show that persons with disabilities are up to three times more likely to be victims of physical and sexual abuse, and are at greater risk of contracting HIV/AIDS.

Organizations of persons with disabilities fully participated in the negotiations and had a significant impact on the drafting of the Convention. The treaty provides for the creation of national independent structures responsible for its implementation and monitoring. Persons with disabilities and representatives of disability organizations are to be members of such bodies.

## **Persons with disabilities are empowered**

For countries ratifying the Optional Protocol to the Convention, a body of experts will be able to consider complaints from individuals or groups on inadequate implementation of the treaty, once all national recourse procedures have been exhausted.

The Convention gives persons with disabilities a powerful tool. *"The mere existence of the Convention gives persons with disabilities and their organizations the ability to say to their governments, 'You have accepted these obligations', and insist that they be met"*, said Don MacKay, the Chairman of the committee that drafted the treaty.

But to realize the rights enshrined in the Convention, a fundamental change of attitude is necessary. *"Disability"*, says the Convention, *"results from the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society"*. Changing attitudes towards persons with disabilities will be necessary to make the objectives of the Convention a reality.

*"It is all a matter of breaking down negative perceptions"*, said Chris Sullivan, a Merrill Lynch Vice-President who was born hearing-impaired. *"You have to look at the person and not at the disability. That requires a tremendous change of perception in everyone."*

For further information, please visit <[www.un.org/disabilities](http://www.un.org/disabilities)>

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*The Convention on the Rights of Persons with Disabilities received its 20th ratification on 3 April 2008, triggering the entry into force of the Convention and its Optional Protocol 30 days later. This marks a major milestone in the effort to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms of persons with disabilities, and to promote respect for their inherent dignity. In a 3 May 2008 News Release, the Australian Government welcomed the milestone, noting that "Australia was among the first to sign the Convention [on 30 March 2007] and the Rudd Government is committed to becoming a party to it [ratifying it] as quickly as possible. A National Interest Analysis will be tabled in the Parliament in the coming months. The Rudd Government will also soon begin consulting the States and Territories on the Optional Protocol to the Convention."*

# Post-Polio Network Office Co-ordinator's Report

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**George Laszuk  
Office Co-ordinator**

Greetings once again from the Office and I hope you all have had a good Easter and Anzac Day break and are keeping as well as possible as winter approaches.

Our Office in Parramatta now plays an important part of the Network's ability to service our members and increasingly relieves various tasks from overworked Committee members. The Office also provides a more accessible location for members to visit and provides our Network with a sense of identity in the eyes of the public. I encourage you all to drop in and say hello from time to time.

Since opening the Office approximately four years ago the most frequent enquiry from our members is "*Do you know of a medical practitioner or specialist who understands or has empathy for people with the late effects of polio?*". Even though we have a list of Rehabilitation Specialists who are familiar with both polio and its late effects, we have found that these doctors do not cover all areas of need. If any member has consulted a medical practitioner or specialist or other health professional (for example: physiotherapist, respiratory therapist, orthotist, podiatrist, occupational therapist, speech pathologist, psychologist, dietician) who they have found to be knowledgeable about the late effects, or who is interested and willing to learn, could you please get in touch and tell us their contact details. As well as expanding our resource file, they can be included on the *Network News* mailing list so they can keep up-to-date with post-polio research and treatments.

I would like to take this opportunity to show my appreciation of and thanks to the Lions Club of Mount Druitt for their support and generosity towards our cause. Over the past four years they, and other NSW Lions Clubs, have raised over \$25,000 in support of our post-polio awareness project which has greatly contributed towards running the Office. Our biggest obstacle in keeping our Office viable is of course funding; as you are probably aware we receive no government assistance and rely solely on donations and subscriptions to provide our services. If any members can offer assistance or give us ideas for raising funds, please contact me or any member of the Committee.

The current Office roster is given below. Apart from my regular days you will find me in the Office on various other days of the week as I train and keep in regular contact with all our volunteers as well as ensure the Office is staffed whenever someone can't come in or is on leave. After two years working as a volunteer in the Office, Noelene has now left to spend more time with her family. We greatly appreciated her commitment over this considerable period and wish her well for the future.

Monday	Tuesday	Wednesday	Thursday	Friday
Ray & George	Nola	Carlie & Shylie	George	Carlie & Shylie

Goodbye for now – I hope to catch up with some of you in person at a Seminar this year.

# Support Group News

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I have been managing to travel around the state a bit more in recent times. I will be visiting and calling on the assistance of many Support Groups and their members to assist me with a project which should be of benefit to our membership. Through my further involvement with the Physical Disability Council of NSW we are designing a questionnaire which will survey the needs of people who are ageing with a disability. The data collected from this survey will be taken directly to the Department of Ageing and Disability for inclusion in future planning. We are hopeful that this may bring results which are beneficial to our members.

With the assistance of members of the **Albury/Wodonga Support Group**, we have trialed the prototype of the survey and thanks to their involvement, have been able to produce the final version of the survey. I am very grateful to members for their valuable input.

On 12 April I met with friends in the **Northern Rivers Support Group** at Lismore Workers Club. I provided an update on Network activities and members very willingly completed the Ageing with a Disability survey. At a breakfast meeting at Ballina RSL Club on Sunday, 13 April I was able to supply surveys and addressed envelopes for those who could not be in Lismore. My thanks are expressed to Rosalie Kennedy for making all these arrangements.

The **ACT Support Group** had an additional meeting on Saturday, 24 May so that I could address the meeting on upcoming events and present the survey for completion. Thanks to the goodwill of co-convenor, Roger Smith, we were able to meet at his residence at Pialligo. My special thanks go to all members who made the effort to attend and make my visit worthwhile.

On 16 April I travelled to **Wagga Wagga** again to be further involved in their arrangements to host the 2009 Country Conference which will be held in Wagga Wagga during September. The Wagga Wagga group are making arrangements to attend a special Polio Day in Albury in October being arranged by Mary-ann Liethof from the Victorian Polio Network. My thanks go to members for completing the Ageing survey.

At the conclusion of the June Seminar (presenter Craig Knox from Lismore will speak on the topic: *Orthopaedic Surgery Recovery and the Polio Patient* – see page 2 for full details) I will also present the survey for members who may wish to participate. In early July I will travel to the **Hunter Area Support Group** for a long overdue visit.

We convey our sincere condolences to Ron Smith of Tamworth on the sudden passing of his wife, Jeanette, in January. There will not now be an attempt made to form a Support Group in the Tamworth area unless a member in the area is prepared to volunteer their services as convenor. We thank Ron for his commitment to the Network and wish him well for the future.

# Polio Particles

## Mary Westbrook

*Polio Particles, written by Mary Westbrook, reports information and stories about polio, post-polio and disability issues of interest to polio survivors. These include press reports, research findings, book reviews and updates on polio eradication and immunisation. Polio Particles is syndicated in post-polio newsletters internationally.*



## Failure to vaccinate against polio means jail

Under Belgian law polio vaccination is mandatory. The only other country that has taken this step is France, although Saudi Arabia demands that pilgrims to the yearly Hajj pilgrimage who come from countries in which polio is endemic must prove they have been vaccinated. They are also given another dose of vaccine when they arrive in Saudi Arabia 'just in case'. The *British Medical Journal* reported in February 2008 that two sets of Belgian parents who refused to have their children vaccinated against polio had been fined the equivalent of just under \$A9,000 and sentenced to five months imprisonment. The sentence was suspended while the parents were given a second chance to vaccinate their children. These events received much publicity around the world. Privacy laws in Belgium prevent publication of details about cases so it is not known how much time the parents were granted or why they refused to vaccinate. I have not found any reports on what the final outcome has been. Belgian law allows for an exemption to vaccination if it can be proved that the child would be adversely affected. The case attracted attention from bioethicists. Associated Press (12/3/08) quoted Professor John Harris, University of Manchester, as saying: *Nobody has a right to unfettered liberty, and people do not have the right to endanger their kids. The parents in this case do not have any rights they can appeal to. They have obligations they are not fulfilling.* Dr Ross Upshur, University of Toronto, said: *It's a pretty extraordinary case. The Belgians have the right to take some action against the parents, given the seriousness of polio, but the question is, is a prison sentence disproportionate?*

## Getting up from a chair

The Winter 2008 issue of Post-Polio Health International's newsletter contained an informative letter from Clara Reiss, who needs to use her arms to get up from a chair. Recently when two physiotherapists saw Clara getting up *with my hand placed on the chair arms so that my fingers pointed toward my body, my elbows away from my torso they screamed together "Don't do that!"* as it could tear her rotator cuff muscles. They instructed her *to place my hands on chair arms in the opposite way, with my fingers pointing out, away from my body, leaving my elbows close to my torso.* Within a month shoulder pain that had been troubling Clara had disappeared. The newsletter obtained the views of several physiotherapists who agreed that the way suggested is better but Robbie Leonard pointed out that some survivors who *use unusual positioning for performing functional techniques do so because they are using the muscles that they have.*

## Cognitive fatigue in polio survivors

At the American Neurological Association's Conference in October 2007 Dr Olavo Vasconcelos and colleagues presented the results of a research study into *cognitive fatigue in survivors of paralytic poliomyelitis.* The researchers used computerised tests to investigate the effects of fatigue on polio survivors' mental functioning. Survivors who participated did not show any signs of diminished mental functioning when well rested.

During the investigation the survivors were given a set of tests known as the ANAM (Automated Neuropsychological Assessment Metric). After an hour's break they were given the tests a second time. Most people improve on a second attempt at these tests due to having had previous practice but the scores of more than half of the polio survivors decreased. Analysis of the survivors' actual answers indicated that the decrease in their scores was not due to a decline in survivors' accuracy but to increased reaction times as a result of fatigue.

## **Search for disabled models**

According to *The Guardian* (5/3/08), the BBC is planing a five part TV series with the working title of *Britain's Missing Top Model* in which *eight women with disabilities compete over three weeks to prove to a panel of industry experts that they have what it takes to be a mainstream fashion model ... "Our intention is to empower both the women featured in the project and thousands of others, who shouldn't be invisible to the fashion industry, just because they are disabled people"* says director Richard McKerrow. The series *will follow the chosen women as they move into a London apartment together and are trained in every aspect of modelling from posing for photoshoots to location work and catwalks.* The BBC, which is receiving support from disability organisations, is searching for women with disabilities, aged between 18 and 30, to participate.

## **Link between pain and fatigue**

Chronic pain and fatigue often coexist. *As many as 76% of people with chronic, widespread musculoskeletal pain report fatigue; and as many as 94% of people with chronic fatigue syndromes report muscle pain* according to Dr Lynn Burnes and colleagues, in an article published in the April 2008 issue of the *American Journal of Physiology*. Women make up the majority of patients with conditions involving pain and fatigue eg chronic fatigue syndrome and fibromyalgia. Burnes' team have demonstrated a biological link between pain and fatigue which may help explain why more women have these conditions. The team bred mice that had high or low levels of ASIC3 (an acid-sensing ion channel present in muscle) which is involved in musculoskeletal pain. They then compared the fatigue following exercise of groups of male and female mice who had high or low ASIC3. Various groups of mice did tasks such as three one-hour runs. The researchers then tested the mice's fatigue by measuring their temporary loss of muscle strength. One of their complex findings was that high ASIC3 male mice showed less fatigue than high ASIC3 female mice after completing the runs. However when high ASIC3 female mice were given testosterone, their muscles became as resistant to fatigue as those of the high ASIC3 male group. However low ASIC3 female mice's fatigue levels were not helped by testosterone. The researchers concluded that *there is an overlap between fatigue and pain such that fatigue plays a significant role in the development of pain and pain is enhanced in response to fatigue.* In an interview with *Science Daily* (9/4/08) the researchers said: *The differences in fatigue between males and females depend on both the presence of testosterone and the activation of ASIC3 channels which suggests that they are interacting somehow to protect against fatigue. These differences may help explain some of the underlying differences we see in chronic pain conditions that include fatigue with respect to the preponderance of women over men ... Our long term goal is to come up with better treatments for chronic, widespread musculoskeletal pain. But the fatigue that is typically associated with chronic, widespread pain is also a big clinical problem — it leaves people unable to work or engage in social activities. If we could find a way to reduce fatigue, we could really improve the quality of life for these patients.* I speculate about whether the findings will have relevance to post-polio syndrome which surveys show is more prevalent among women than men. This difference has sometimes been attributed to social factors such as women being more likely to admit to health problems, join support groups, take

part in surveys etc. In other words, the implication is that the surveys are not picking up many unidentified male cases in the community. While there may be some truth in this it might turn out that women polio survivors are more prone to some of the symptoms of PPS or experience them more severely.

## Historic polio-free achievement in Somalia

Polio was eradicated in Somalia in 2002 but the country became reinfected in 2005 when the virus travelled from Nigeria and 228 Somalian cases occurred. On March 25th 2008 Somalia was once again declared polio-free as there had been no cases in the previous year. This success was due to the over 10,000 volunteers and health workers. They immunised more than 1.8 million children under five years of age in what has been described by Rotary International, which contributed \$US9.2 million to the Somalian campaign, as *one of the most dangerous countries on earth*. One of the volunteers was Ali Mao Moallim, the last person to contract smallpox before it was eliminated from the planet in 1977. He said that *Somalia was the last country with smallpox. I wanted to help ensure that we would not be the last place with polio too*. Dr Costales a senior advisor with UNICEF said, *Somalia beat polio in the midst of more widespread conflict and poverty than that affecting Afghanistan and Pakistan ... Somalia shows that when communities are engaged, children everywhere can be reached*. (Information from a Rotary International press release 31/3/08)

## Not walking

Professor Lisa Iezzoni of the Harvard Medical School, has MS and uses an electric scooter/wheelchair. She has written *When Walking Fails* (Published by University of California Press, 2003), a book about the effects of mobility problems. Several points in this interesting book of over 350 pages particularly caught my attention. She discusses how we are affected by society's views that walking connotes *independence, autonomy, perseverance, strength, achievement* — *'standing on your own two feet', 'walking tall', 'standing up for yourself', 'taking things in your stride'*. Conversely *societal views of walking problems remain a complex tangle of fears, discomforts, sorrows, rages and uncertainties* which make the notion of needing a wheelchair terrifying. *The phrases 'wheelchair bound' or 'confined to a wheelchair' imply that a wheelchair restricts the individual, holds a person prisoner*. In reality a wheelchair is a tool, the use of which enhances quality of life. Social attitudes toward walking also influence doctors. Iezzoni considers doctors often keep patients struggling with ambulation, insisting they must 'use it or lose it'. *For many people with progressive chronic conditions, however, this belief isolates the legs from the whole person. It assumes that the primary objective is to maximize failing muscle function rather than consider the totality of a person's daily life. Those who look beyond physical functioning believe it is ultimately more important and cost-effective to improve a person's quality of life*. She discusses Eleanor a polio survivor who was having so many severely damaging falls she *fought* with her doctors to get a wheelchair. Eleanor said that doctors *felt if I started using the chair I would lose more muscle in my legs. That wasn't the case because I don't sit in a wheelchair all day*. Eleanor walks around in her office and at home. For her as for many polio survivors a wheelchair is not an all or nothing option.

Like many survivors I've gone through the 'getting a scooter / crutches / a wheelchair makes this the worst day of my life' feelings. Advantages I noticed immediately when I began using a wheelchair were that being in a queue was no longer excruciatingly exhausting, it was no longer a terrible hassle if I left something in another room and had to go and get it, I could easily move round and talk to people when I went to an event such as a Network Seminar, I could carry lots of stuff around including grandchildren (all impossible on crutches), I was much better humoured as I wasn't so tired, and shopping was fun once

again. The world isn't surfaced in flat concrete so of course wheelchair travel is not always trouble free. As lezzoni says, she *desperately wished to walk, but since I couldn't go far I decided to roll. Now I do and it's terrific! In a real sense, this book is a paeon to my wheelchair.* She quotes journalist John Hockenberry, a paraplegic from spinal injury. In his autobiography, *Moving Violations*, John wrote: *It took years of being in a wheelchair before I could be truly amazed by what it could do, and what I could do with it. On a winter night in Chicago, after a light snow, I rolled across a clean stretch of pavement and felt the smooth frictionless glide of the icy surface. I made a tight turn and ... I saw two beautiful lines etched in the snow. They began as parallel and curved, then they crossed in an effortless knot. ... My chair had made those lines. The knot was the signature of every turn I had ever made ... It was the first time I dared to believe that a wheelchair could make something, or even be associated with something, so beautiful.* Well, I have not encountered any light snow in Sydney but I find I get a great buzz gliding in my wheelchair, past everyone, down the slopes of a shopping mall. I haven't moved so fast since polio caught me aged eleven. I can almost feel the wind in my hair.



## Companion Card for Carers

People in NSW who have a severe or profound disability will now be able to take a carer on public transport and to events for the prices of a single ticket.

On 20 April 2008, the NSW Minister for Disability Services, Kristina Keneally, announced that the NSW Government will introduce the Companion Card to assist people with disabilities who need a carer to better participate in the community.

*"The Companion Card recognises that a carer is indispensable to a person with a profound or severe disability and gives them equal access to services and facilities like everyone else", Ms Keneally said.*

*"The NSW Government will provide the card to people who always or usually require the assistance of a carer in their daily lives, with eligibility based on the needs of a person with a disability.*

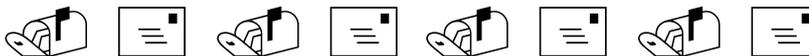
*"The card will be free, it won't be means tested, and we estimate it will make it easier for about 25,000 people in NSW to better access the community, everyday services and events.*

*"In addition to public buses and trains, we believe there will be strong support for the card from the private sector, particularly entertainment and sporting businesses."*

Ms Keneally said the new Companion Card will be introduced this year.

*"Based on the experience of states who have introduced a similar scheme, we know that it will take six months or more to set up the Companion Card – so we are looking forward to introducing the service in mid to late 2008", Ms Keneally said.*

*"In the interim we will continue to work with the Australian Government to make the card a national scheme which delivers benefits to people with significant disabilities across NSW and the country."*



*It was with sadness that we learned recently of the passing of one of our long-term members, Joyce Corbett from Forster, at the age of 92. Joyce's daughter, Anne Schubert, wrote a moving letter to give us the news and I sought her permission to share her mother's story with you.*

Sadly our Mother recently passed away. However she was 92 and lived a brilliant life, even though she had contracted polio at the age of 11 months. Every step she ever took was an effort – we knew because we could see, however, never did she complain or bemoan her fate.

Our lives – she bore 5 children – were always full and interesting, as she and Dad took us on holidays to the Zoo, Luna Park, the country, the city, anywhere that was stimulating or interesting. She never allowed the huge restriction in walking to hinder the normal functioning of our busy household.

It was through your publication we became aware of the after effects of polio and when Mother finally fell breaking her leg in her 80's we began to truly understand what a courageous woman she had been.

Her last years were wheelchair bound and once again her fierce independence and indomitable spirit kept her busily occupied in historical societies, senior citizen activities, old school lunches and finally all the goings on at her Aged Care Facility.

It has always fascinated me when those who met her would feel sad because of her "affliction" when neither she nor all of us ever thought that she was disabled at all. That was her legacy to her whole family: "Love everybody, love everything – make the most of every moment".



*You may recall that in the last Post-Polio Post I published a letter from Susan Murphy of Tuncurry. Susan is on a mission to help her husband who is having health problems which his specialists think may be due to exposure to chemicals while in utero. Susan sought advice from any Network member who may be aware of chemical spraying in the homes of those who contracted polio. Susan has now written again to thank the Network members who contacted her as a result of her plea, and excerpts from her letter appear below. If anyone has further information for Susan you can write to her at 8 Guy Place, Tuncurry NSW 2428.*

I have enclosed copies of two responses as they state both private and public buildings were fumigated for the polio virus. I had over 25 phone calls in response to my letter in the *Telegraph*; some were members of your Network.

There were some horrible stories about fumigating people. One family was removed from their home and placed in the back of an ambulance and sprayed, families told to leave their homes and a workplace closed down, due to being fumigated.

One man I heard from has the nickname "Weeds". His friends still call him this today. He was given the nickname "Weeds" as when he was a child he contracted polio and he was sprayed so many times that the nickname stayed with him.

Some people must have found it very difficult to write/phone as they had to recall horrible memories. One lady who had polio stated that their home was fumigated when she was ill and then again six months later when her sister contracted polio. Her sister died as a result of the polio virus. There were a couple of victims who didn't realise that their homes were fumigated until they contacted other relatives.

Gillian, once again thank you to all your members who were generous enough with their time in phoning or writing to me. Also, thank you so much for printing my letter in your *Network News*. Hopefully, some of your members who may not have known are now aware that strong chemicals could have been used in their treatment and in their family homes or even workplace. I will continue to search for answers to explain my partner's illness.



# 2008 Post-Polio Network Seminar Program

<b>Saturday 14 June 2008</b>	Ryde-Eastwood Leagues Club 117 Ryedale Road West Ryde	<b>Orthopaedic Surgery Recovery and the Polio Patient</b> <i>presented by Craig Knox</i> Physiotherapist, Lismore Base Hospital <b>Please see full details on page 2</b>
<b><u>Now on</u> Saturday 6 September 2008</b>	The "Tradies" Club 57 Manchester Road Gymea	<b>The Baribunma Wheelchair</b> See this revolutionary electric wheelchair (which can potentially return the freedom of the road to you) demonstrated by its designer <b>Wally Bancroft</b> <b>Please note the changed date</b>
<b>Saturday 22 November 2008</b>	Burwood RSL Club 96 Shaftesbury Road Burwood	<b>Annual General Meeting and Seminar</b> <b>Mary-ann Liethof</b> from <i>Polio Network Victoria</i> will report on her <i>Churchill Fellowship</i> study tour to the USA and Canada where she aims to "identify techniques to better manage the late effects of polio"

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# About the Network

The Post-Polio Network (NSW) Inc was formed in 1989 by polio survivors for polio survivors.

It is a self-help, self-funded organisation run entirely by volunteers. The Network provides information about polio's late effects and supports those who may be affected now or in the future. The Network conducts quarterly Seminars, publishes *Network News* and *Information Bulletin* quarterly, fosters the establishment of regional Support Groups throughout NSW and the ACT, and maintains a comprehensive website.

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

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 the Network's income which is used to provide its services comes from membership subscriptions and donations.

## Resources for Members

On joining the Network, 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.

The Network also stocks various publications which further describe the late effects of polio and their management. The prices quoted below are for Network members and postage is included. To order, just write to the Network – please make cheques / money orders payable to Post-Polio Network (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>The Late Effects of Polio: Information for Health Care Providers</i> Charlotte Leboeuf	56 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>
The Network has its own 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 the Network. Not only is the badge a great fashion statement, it is an innovative way to promote the Network.	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 Network.