

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 still not been received. I will continue to follow this up with a view to publishing it in the next *Network News*. We have however received an article from our most recent Seminar presenter, Craig Knox, and you will find this on pages 3-5.

On page 2 you will find full details of our upcoming Seminar demonstrating the Baribunma Electric Wheelchair which will be held in southern Sydney on Saturday 6 September. Please show your support for both the Seminar organisers and the speakers by coming along, particularly if you live in the area.

With the reduced numbers on the Management Committee this year (7 out of a possible 12) we have been giving consideration to how our workload can be reduced so we don't overstretch ourselves. We no longer have the capacity to produce both a quarterly *Network News* and a quarterly *Information Bulletin*, and have therefore taken the decision to incorporate the *Information Bulletin* within *Network News*. From this issue onwards you will find a regular feature *Helpful Resources* which will be compiled and updated by our Office team. You will find the first edition on pages 19-20.

As also promised in the last *Network News*, we are starting a regular feature of members' polio stories under the heading *Our Polio Legacy*. This issue includes two such stories (pages 11-16) which I'm sure you will find interesting reading.

If you can contribute to either of these initiatives we would love to hear from you.

Our other major decision concerns our Seminar Program. In recent months the Management Committee has become increasingly concerned about dwindling numbers attending Seminars. This, coupled with the growing costs to the Network of putting on the Seminars (due to venue costs) and the effort involved in actually staging the events, has necessitated a re-think of how we present information to members. For 2009 we have decided to trial a new Seminar format which will see two metropolitan events staged rather than four as has been the case in the past. The first Seminar next year will be held during May and will take the form of a day-long Mini-Conference with several speakers presenting different topics. The Mini-Conference will be held at the Northcott Society premises at Parramatta and will include lunch at a nominal charge. This format is similar to the very successful events we hold in country NSW every second year; in 2009 there will be a Mini-Conference in Wagga Wagga. The second metropolitan Seminar, to be held at the Burwood RSL Club in November, will have only one speaker as usual but will include our Annual General Meeting and lunch at no charge. Of course, any gold coin donations on the day to help defray the catering costs will be appreciated. We hope that this revamped Seminar Program will enable a broader range of topics to be covered which will attract more members. We will be keen to get your feedback on both the concept and its implementation next year.

Another initiative which is underway is the enclosed Support Group survey which we encourage all members to complete and return, whether or not you currently participate in a local Group. Here again attendance in many Groups is declining and, in recognition of our decreasing mobility and stamina and increased disability, we need to determine the best structure to keep the Support Group network viable and of value to its members.

Finally, a reminder that we are still looking for more Committee Members, and in particular a Treasurer, to join our hard-working volunteer team. If you are able to give something back to the Network which supports you we would be very grateful to hear from you.

We look forward to catching up with as many members as possible at our Seminar on 6 September.

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Seminar - Getting "On The Road Again" !

- Date:** Saturday, 6 September 2008
- Time:** 1:30 pm – 4:00 pm (*please note slightly later starting time than usual*)
- Venue:** Bass and Flinders Room (*this may change depending on numbers*)
The "Tradies" Club
57 Manchester Road (Corner Kingsway), Gymea
For location information, visit <www.tradies.com.au/map.cfm>
- Lunch:** Bringing your own lunch is not an option at this venue
Lunches (from light to full meals) are available from the *Brasserie*
The Eureka Café has snacks, foccacias and sandwiches
- Afternoon Tea:** Courtesy of the Network – ***please RSVP by Tuesday 2 September***

Our September Seminar will be presented by Wally Bancroft and Geoff Denyer from Baribunma Mobility Systems. Wally Bancroft has over twenty years experience in modifying equipment to suit people with disabilities. Over the past fifteen years he has designed and built many wheelchairs for people with varying disabilities. Through this work Wally has developed the design of the Baribunma Electric Wheelchair to provide a mass produced chair with numerous advanced features. Wally and Geoff will be demonstrating this internationally patented transportable wheelchair. It has been thoroughly developed and tested over ten years to allow a disabled user to safely transport themselves with maximum independence. Their testing regime has included a variety of motor vehicles (both as a passenger and driver), public transport and aircraft! The Baribunma is the only electric wheelchair, worldwide, to pass an automotive Crash Test, ADR 3/02.

The Baribunma Electric Wheelchair will allow virtually any seating requirements to be mounted which makes it suitable for use in a variety of vehicles with minimal or no modification. Existing wheelchairs require a vehicle to be structurally modified to allow entry of the wheelchair to the vehicle and restraint accessories to be fitted and certified by an engineer to fasten the chair during travel. This is mainly due to the inability of existing electric wheelchairs to reduce sufficiently in height to clear the access door(s) of the vehicle. Structural change can cause damage to a vehicle by affecting its structural integrity, significant added costs are involved and, in the long term, corrosion can occur. Typically, these structural changes involve lowering of vehicle floors, raising of vehicle roofs, fitting of commercial "hoists" or a combination of these solutions. The Baribunma Wheelchair can adapt to fit most commercially available people-mover vans by reducing sufficiently in height to allow ready access. Furthermore, with smaller wheels and a small, easily fitted, lockdown, the Baribunma Wheelchair needs no costly restraints or further engineering certification.

The Baribunma standard features include ♦ Fully Height Adjustable, ♦ Full functionality at all height settings allowing comfortable seating at tables/desks, and ♦ Easy transfers.

As usual, this will be an interactive session with not only plenty of time available for questions but also the chance to have some hands-on experience with the Baribunma.

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> to confirm your attendance.

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 2 September to confirm you are coming.

We look forward to seeing everyone there and hope that the move to Gymea 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.

To Replace ... or not to Replace ... That is the Question !

Is a total joint replacement appropriate for a polio survivor ?



Craig Knox, Physiotherapist and Orthopaedic Care Co-ordinator for Joint Replacements, Lismore Base Hospital, 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 our June Seminar. Since 2002 Craig 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 that he knew were affected by polio. Craig firmly believes that there are variations in the way that polio and non-polio patients should be treated, both before and after a joint replacement.

The primary reasons for a joint replacement are osteoarthritis 90%, rheumatoid arthritis 4% and trauma/other reasons 6%. Studies show that up to 96% of joint replacement surgeries are successful. However, there are some pre-operative conditions that may assist in predicting whether your surgery will be successful.

If you have an osteoarthritic knee or hip on your “unaffected” side, then chances are you fit in the 90% of joints that have “worn out”, and generally you have a high chance of successful joint replacement surgery.

If you are considering your “affected” limb for surgery, there is usually a different reason why your joint has worn out. This is usually from long-standing poor biomechanics, or alignment, caused by reduced muscle function in and around your joints, as a result of the polio virus. Associated with the weaker muscles are a variety of problems such as leg shortening, joint malformation (the joint never formed correctly), ligament laxity (loose joint), and a variety of other surgical interventions (such as ankle fusions, tendon transfers and so on). There has often been the need to wear callipers or prostheses to support the affected joints to compensate for these problems. Generally, a joint replacement can remove the affected painful joint surfaces, but it cannot fix these other pre-existing problems, and it is also these pre-existing problems that can limit your chance of getting good function from a joint replacement.

It has been shown in the general population that if you have weak quadriceps (the muscle at the front of your thigh) then you have a decreased chance of successful knee replacement surgery. Apply this assumption to a post-polio person, whose leg also hyper-extends (bows backwards at the knee) and is often “knock-kneed”, then the outcomes look even poorer. In fact, a study has shown that 50-60% of patients are worse off after their surgery. If you walk with your knee locked back you are doing this to make your leg stable, so it doesn’t collapse under you. If you have a knee replacement, you run the risk of not being able to lock your knee back, and hence lose that stability of the knee, and potentially lose the ability to walk. If you are able to still lock it back, the forces that you place on the new knee will ultimately lead to premature failure of the new joint, and mean further surgery.

It is also demonstrated that weak quadriceps also mean a higher chance of shoulder problems, as the person generally has to use their arms to pull or push their body around rather than use their legs. With any person having a joint replacement there will be an increased demand on their shoulders in the initial post-operative period, potentially exacerbating any pre-existing shoulder problems, which may in turn cause extra stress on the newly operated joint before it has fully recovered from the surgery.

Orthopaedic surgeons have described joint replacement in a post-polio person as “an uncommon and technically challenging procedure”, which implies that if you want this operation, you should be considering a surgeon with experience in this type of surgery.

Exercise forms an integral part of any joint replacement surgery, both before, and after the surgery. Your ability to exercise muscles needs to be assessed to determine how hard you are to work these muscles, if indeed you should work them at all.

The following grading system (developed by Kendall) has been used by therapists working specifically with post-polio people, to assess muscle groups in an attempt to decide whether or not exercise is appropriate:

- Grade 1 Flicker only
- Grade 2 Full ROM no resistance
- Grade 3 Full ROM against gravity
- Grade 4 Full ROM against moderate resistance
- Grade 5 Full ROM against maximum resistance

ROM = Range Of Motion

As a guide, muscles that score 3 or less should NOT be exercised, as there is a risk that the muscles will fatigue further, and actually decrease in strength. These muscles are barely coping with your day-to-day activities, without the added stress of exercise.

Grades 4 to 5 have been shown to be able to exercise “with caution”. This means you complete an exercise up to 5 times only (usual gym programs suggest 3 sets of 10 repetitions), at 50 – 70% of your maximal strength capacity. Recovery time is usually 2 days between exercises.

There would be a preference to work on endurance programs with flexibility components rather than on pure strength programs.

You need to modify your program (preferably in liaison with your therapist) if you notice an increase in pain, increased time to recover, increased fatigue, and definitely if there is an increase in weakness.

Some may say this is common sense ... the trouble is that “common sense” is usually not that common!

The adage “no pain, no gain” quite probably doesn’t apply to the post-polio person, which may be difficult for a few people to grasp as I am guessing that throughout your lives you have been pushing the pain/stress boundaries on a daily basis. It seems though that post-polio brings with it a new set of rules, that potentially causes more weakness to muscles that may have coped quite well over the last 40 years, without any damn reason !!!

If you do decide that you are appropriate for a joint replacement, then your approach needs to be a positive one. Setting goals for your recovery will help you achieve the success you desire, but perhaps a little more slowly than the “mainstream” person. It would be worth while linking in with a physiotherapist PRIOR to your surgery, so that they could assess your current level of function, and possibly to have time to do a little research themselves on the expected performance abilities of a post-polio person. As this is still deemed a relatively uncommon problem by therapists, then the chance of them having had experience in its treatment will be low. However, most physios by nature are inquisitive, and will endeavour to expand their knowledge on the subject so that they can help you as best they can. You will be “helping yourself, by informing others”.

Social support is possibly the biggest determinant as to the success of your surgery. Those with supports generally perform better at home. Those lacking close support may need to consider the value of a rehabilitation type of extended stay in an institution to ensure the extra time needed is available to progress your mobility at a slower pace.

Many post-polio patients report a major decrease in stamina following illness, surgery or trauma. By planning to expect this, you can make necessary adjustments to your post-operative care to allow for it. Hopefully by being aware of what to expect there won't be too many "surprises" to upset your recovery, and if you don't experience the difficulties then that would be considered a bonus.

After discussing things over with your orthopaedic surgeon you feel that you are not appropriate for a joint replacement, then other lifestyle changes can be of assistance. Perhaps a procedure where the joint is fused may be more appropriate for you.

Pacing is probably the most appropriate lesson to be learnt. Spread your load of chores across a week. Farm out chores that someone else can expend their energy on, while you save your energy for fulfilling activities that you actually enjoy. If any one tells me "they love scrubbing floors" I make an immediate referral to the nearest Mental Health Team! Ensure rest periods are taken to recover from strenuous days.

Learn to say NO....

Judicious use of aids such as electric scooters save a lot of energy for your destination, rather than expend yourself just getting there.

An occupational therapist review would assist in all of these ideas, and would be highly recommended NOW, rather than later. Perhaps this could be an idea for a guest speaker at a later gathering?

This information is to be used as a guide to your post-polio management only. Any decision regarding surgery must be made with all relevant information at hand, in conjunction with your medical team (GP and orthopaedic surgeon). This may appear to be quite negative but, as with any information, you should process the ideas and apply them to your own individual situation and hopefully you will make the most appropriate decision on your management.



A Great Day for Australians with Disability

Human Rights Commissioner Graeme Innes welcomed the announcement on 18 July 2008 of Australia becoming a party to the international Convention on the Rights of Persons with Disabilities and called for governments to act to make the rights in the Convention a reality.

"Sixty years ago this year, in the Universal Declaration of Human Rights, the world affirmed that human rights had to be universal," said Commissioner Innes. *"The Convention on the Rights of Persons with Disabilities gives long overdue recognition that, if rights and freedoms are to be truly universal, they have to include people with disability."*

The Commissioner noted that Australia is among the first nations to ratify the Convention. *"I commend the Government for moving swiftly to ratify the Convention on the Rights of Persons with Disability,"* said Mr Innes. *"I'd also like to recognise the previous Government for their strong support of the Convention, which included signing it on the first day it was open for signature, and playing an important and positive role during the drafting process in partnership with disability community organisations."* More than one fifth of Australians are estimated to have some kind of disability and this is expected to increase with the ageing of the population. The Commissioner emphasised that the announcement was not the conclusion of the process of recognising human rights for people with disability.

Benvenuto a Firenze

or part 2 of *My Holiday in Italy* – Anne O'Halloran

Anne's report on the first part of her Italian adventure, where she spent time in Perugia, was published in *Network News*, Issue 74, March 2008. In this second and final part of her holiday report she takes us on an exploration of Florence.

The trip by train across Umbria and part of Tuscany skirted Lake Trasimeno and made several stops on the way to Florence; one stop I was particularly interested in was Arezzo where the film "*Life is Beautiful*" was filmed. However I only glimpsed parts of the town and the station on the way through. During the journey a couple of fellow travellers tried to converse with me and, while I explained (*in Italian*) that my Italian language was limited, we were able to make some kind of connection. I found these experiences fun and exhilarating. The trip from Perugia to Firenze took 2 hours 40 minutes and the train was almost full by the time we reached our destination, mainly with young people with no baggage who were travelling between stations.

As promised, at SMN stazione Firenze I was met by two assistants with a wheelchair at the door of the carriage (*in Florence the door was level with the platform*). My bag was carried off and I was whisked away to the taxi rank to pick up a taxi to the hotel I had booked for two weeks as planned.

Florence was much busier than Perugia. Hotel Azzi or Locande degli Artist (*I am sure I was romanced by this name, which I think translates to "Inn of the Artists"*), turned out to be a very temporary VISIT rather than a two weeks stay. I had booked by internet (*and I offer some sense of warning to readers following my experience, especially if requiring special access*). In my emails I had requested a ground floor room or use of a lift and private bathroom ... instead my bedroom was to be on the second floor up a winding staircase, quite wide enough but still plenty of climbing and no lift. The 'private' bathroom was private alright but involved a walk along a fairly public corridor from the bedroom and the actual bathroom was 'an accident waiting to happen' for me with its entrance up three steep high steps (*no rails*) and the toilet bowl opposite the shower recess with no hob or curtain to contain the water.

I refused to take it and showed them their reply to my email. This was the only real hiccup in my holiday and I began to wonder where I would start to then look for other accommodation and whether I could communicate my needs in Italian over a phone. I was grateful to the young receptionist, who at first was disputing my original request; however she listened and understood then telephoned another hotel who had a room with easy access and a lift. She told me the price (*it was much dearer but what the heck I had waited 44 years!*), then rang for a taxi to take me there.

Hotel della Pace was a small comfortable hotel and not far from some of the great sites and local bus transport.

I was back in business!!!!

I forgot to mention that during the first three weeks of my holiday for my daily excursions I used a "bumbag" around my waist where I carried loose change, travellers' cheques and bus tickets. As well I used a small back pack which freed up one arm for using to get on and off transport ... the other arm was used for my crutch. In my back pack I carried a camera, passport and other essentials, and my mobile phone (*when it worked*).

My mobile was not that useful. I had extended my phone card's value and arranged to have it switched to "roaming" before I left Sydney but did not know that on that system I paid for all **incoming** text messages and phone calls; consequently after several text messages to and from a nephew and a niece in Australia and a few phone calls from Gigi when in Perugia I was advised that I only had 30 seconds left on my phone, so it was packaged away which reduced the daily weight in my small backpack. In hindsight I should have purchased another SIM card. Despite my purchase of another prepaid card in Italy there was some technicality that prevented use.

I also stopped using my "bumbag", it seemed to drag me down now that I was doing much more walking around Florence which is mostly on the flat. I hope that by including these details they might alert others when considering similar journeys.

Avanti a Firenze! As I said, my new "home" was close to many of the famous sights of Florence and I was able to walk to some of them. There was a bus stop very near to the door of the hotel and by this time I was "experienced" at bus travelling and in knowing where to alight and the use of bus tickets and so on.

After the initial set back I was raring to go again.



I was able to discover the frescoes of Fra Angelico at the Church of San Marco (*pictured above*) which was in the Piazza within walking distance of my hotel. I never stop being amazed at the survival of these paintings and being able to see them (*not replicas*) close up.

My plans for Florence included visiting once again Piazza della Signoria where sculptures abound (*a replica of Michelangelo's David is there*), walking across the Ponte Vecchio, a visit to see the art work in the Uffizi Galleria, a trip to the winefields of Chianti, and generally once again to try to communicate with the locals and to just enjoy the atmosphere of being amongst the people, their customs and the history of the city and of Italy. I had been advised by Anna in Perugia that the Fiorintini (*people of Florence*) were very proud of their city and their language (*I was corrected in my pronunciation of Italian in Florence and that was a learning experience!*) which they claimed had originated in Florence – Florence was also once the capital city of Italy.

It was the middle of June when I was in Florence and the temperature on many days was over the 30 degree mark. A couple of days were 35°. Even though it was hot the humidity seemed low. Most people carried water bottles except *me*, because of the extra weight that would have involved. Consequently on one day after riding the buses around the sites and to an outer “suburb” called Settignano, which has historical connections to Michelangelo Buonarrotti, I began to feel a bit woozy and headed for a taxi rank near the station. The long queue of people at the rank were standing in the sun and I began to feel I was “losing it” and headed inside the railway station for a seat. I actually felt as if I was going to faint so sat down and hoped it would pass ... but it didn't!

I was grateful I had learned an Italian phrase asking for help and when I saw who I thought looked like an official I called to him “aiutarmi” (*help me*). He was reluctant to come at first (*may have been my accent!*) but when I added “mi sento male” (*I feel sick*) he replied “ambulanza?”. “No, no” I was quick to reply “un tassi”. He quickly arranged for a wheelchair to take me to the front of the taxi queue and I was on my way back to the hotel where I replaced the fluid and lay down for a couple of hours ... then I was right again. I heard many ambulances on the hot days; I imagine there were others, locals and tourists, affected by the heat. From then on I carried a half full bottle of water with me.

Just down the road from the hotel I had discovered a small electric-type bus with eight seats which conveyed passengers along the narrow streets to the historical sites. The bus was easier to access than the local transport. The latter I still needed to use when I was travelling further afield and found it easier to get on and off from the front door where the step seems to be lower and there are easier rails to grip (*in Italy as in other European countries it was customary to get on at the front and rear doors and off at the middle door, although it doesn't seem to be mandatory nowadays*).

I again received the help that I had experienced in Perugia, that is, when trying to get on at the rear entrance of the bus I was assisted by someone behind who would give my posterior a gentle shove.

Getting back to the small electric bus ... it was great to have transport within level walking distance to the sites that I wanted to revisit. When I turned the corner into the Piazza della Signoria I couldn't wipe the smile from my face. It was so familiar even after 28 years! Twenty-eight years was nothing to this place!!! I enjoyed seeing again all the old buildings, the same famous statues, the atmosphere, the history ... a bit like coming home. The pigeons though had gone because there were now many alfresco restaurants and the buildings were well maintained, painted in colours typical of Tuscany ... pale yellows, tans, pinks etc.

There were also a couple of tourist sightseeing buses which do the rounds of the sites and one is able to get off when they wish.

It took me quite a while to adjust to crossing the roads in Florence because of the direction of the traffic (*opposite to Australia*). I often found myself watching the wrong way and needing to concentrate and refocus my attention.

The Ponte Vecchio was also on my “to do” list and I was able to walk across where famous people and possibly princes (!) had walked hundreds of years before.

I was unable to fulfil all of my plans for Florence, I realised that there was a limit to the hours in *my* day. So I didn’t get to see the art works in the Uffizi Gallery even though it is possible to arrange to visit with a small group and avoid the long queue which forms daily outside the entrance. I didn’t get to attend a musical performance in any of the churches which I had thought would have been something special, instead at night I found an eating place and then headed for “home”. At “home” I could read, or check emails on the hotel computer or watch Italian TV. So maybe (?) I need to return to Florence one day. Fiesole on the hills behind the city became a favourite visiting place and I made several bus trips there where the weather was kinder.

I booked one organised trip to Greve in Chianti to see the vineyards and the olive groves. That included a wine tasting and a tour of a 14th century castle – Il Paglio. I encountered some difficulty again with the tourist bus and the castle because of steps and stairs, however I was satisfied with the trip and the experience of seeing the Chianti region (*remember those Chianti bottles with the basket base that when the wine was finished the bottle was used for decoration?*).

So after two weeks it was “arrivederci Firenze” from me and on to Roma, once again by train and with the assistance of Trenitalia.

My hotel in Roma was again small, accessible for me and right in the city. I could walk outside to shops, cafes and taxis if necessary. In Rome a taxi could be hailed in the street; different to Perugia where you could only engage one at a taxi stand or by phone.

Here I took advantage of the open-top sightseeing bus that visited all the well-known sights. Must admit I didn’t attempt to try the stairs to the top but was happy enough on the lower deck plugged into the multilingual headphones describing the sights.

I love the atmosphere in Rome, so busy and fascinating watching the traffic manoeuvre along narrow streets at breakneck speed. The drivers on the scooters are amazing at finding their way past cars and buses ... I admit though it was a bit hair-raising at times.

Once again I took time to eat outdoors and “drink in” the sounds of cars on the cobbled roads, watching the fashions, tune into the musical language and gestures, and of course satisfy my palate trying different dishes.

Then it was “arrivederci Roma” from me ... feeling a bit sad and wondering whether I would ever return for another visit to bella Italia.

Heading now for home, I had a stopover again at Dubai, this time for two nights. I took the opportunity of filling in the hotel evaluation form and expressed my thoughts about the safety of their bathrooms with disabled access, adding that they could probably find out more information from Novotel in Sydney re the changes to access for ambulant users (*I know the time Terry Fletcher had spent on the Standards Committee*). I was careful not to be too critical of their access; I found many good points for staying at their hotel.

I had done it! A dream come true! The exhilaration lasted for weeks after I had arrived home and I re-lived the days in Italy every time I shared my photos and experiences with family and friends and again when I exchanged emails with the friends in Perugia. The experience seemed to have given me a new lease of life; a feeling of accomplishment.

While writing this I have once again become lost in another time and country; re-lived a summer in Italy.

Where to next?

Another Traveller's Tale

Member Mary Le Clair thinks nothing of packing up her scooter and heading off on an overseas adventure. Recently she had an "interesting" experience in Peru ...

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 guide in the middle called the local constabulary when I "questioned" going in. I was told it was because there may be a bomb in "the machine" !!



I asked a passer by to take this picture and was surprised and pleased that the police went along with it !!

Can You Help to Promote the Network ?

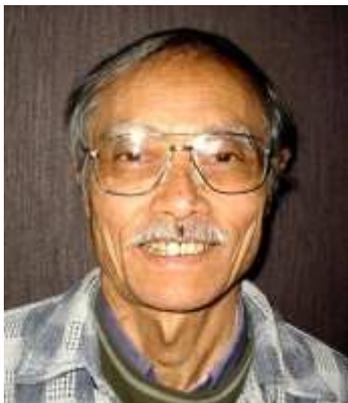
We are most grateful to everyone who has been able to distribute our pamphlets widely throughout their local communities. If any member can help to get the message out about the late effects of polio and the Network by putting more pamphlets on display in, for example, pharmacies, doctors' surgeries or waiting rooms, clinics, shopping centre notice boards, libraries and community health centres, please contact our Office on (02) 9890 0946 (business hours) or by email at <office@post-polionetwork.org.au>, and some will be posted out to you.

Our Polio Legacy

Welcome to the first polio stories in what will become a regular series. We hope that by publishing members' stories in Network News as well as collecting them for posterity we will encourage other members to contribute to the archive. Our stories are a valuable reminder of the effects of polio in an unvaccinated population and deserve to be told and preserved. Stories of any length are fine and can simply be about a memorable polio-related incident or an account of your whole polio experience. Please send your contributions by email to Merle at <stories@post-polionetwork.org.au> or by mail to the Network.

In this issue we feature stories from two members many of you will know, both from their Committee membership and from speaking to them at Seminars: Bing Mak and Len Smith.

MAK, Bing Kwong



This is my poliomyelitis story. My name is MAK, Bing Kwong; my friends know me, and I introduce myself, as Bing. My full name is not very conducive for people not of my background to remember.

The early part of my story below was told to me by my nurse and family, years after the initial event, therefore I cannot vouch for its high accuracy.

My parents went from Guangdong, a southern province of China, to Shanghai to set up a business connection and so I was born there.

I was born a healthy baby, and starting a few months old a live-in nurse came to look after me. Through the years I had developed affection towards her. My mother had given birth to six children and as a young mother she often suffered from physical problems. My father died when I was nine years old. We belonged to a middle class family.

About the age of one year old, a boil had appeared at my back passage and my body suffered from a high temperature. The herbal treatment from a herbalist did not produce relief. Then a foreign (German) surgeon operated on it, as a haemorrhoid. It seemed to recover smoothly until sometime later when I started to learn to walk. My parents noticed that I could not walk like other children. My right leg was sloppy. By then the surgeon said that he could not correct the problem that long after the operation.

My conscious recollection goes back to the time when I was entering kindergarten, six years old – the late start of schooling was due to my disability. I was aware that I was different to my kindergarten mates, and a special chair was made for me to let my right leg, the “bad” leg, to rest upon. This chair lasted no longer than my kindergarten year. I walk, then and now, with a limping gait. During primary school years, often I felt great physical tiredness at the end of a school day, probably due to my weak body and poor nutrition during the war years.

When I was 12, my family moved down to Hong Kong; this was the time of the civil war in China when the communists marched southward and occupied China. In Hong Kong I received corrective operations on my right leg performed by British surgeons. One surgical operation was to graft a posterior tendon of the knee to the front thus supposedly enabling my leg to flex forward. Up to today I am not convinced that this has had a definite help to my movement. At one time, a full length calliper was fitted onto my leg which I found too clumsy, and instead I accepted a knee-high steel one which served me for the next 15 years.

During my adolescent years, my body had a lopsided development – the right side possessed less muscle mass and thus has been weaker. My garment size has always been S or XS (depending somewhat on their countries of origin). There was no restriction to my movements, except that I could not run. My walking companion has to slow down to my speed, and occasionally I urged them to go ahead of me to walk at their pace.

At school, I did not take part in sport and physical education (I cannot remember what I did with those free times). In early high school years, now and then, my classmates would jokingly tease me about my bad leg; it was rather a nuisance than of unkindly intent. In the main, I was taken in as part of the group, the more so towards senior years. The steep hills in Hong Kong had not been kind to me. My walking distance was, and is, considerably shorter than others.

In my early twenties, I came to Sydney for my tertiary education. My low physical endurance did affect and reduce my mental concentration, and my mental power. The journey of a big part of an hour, by train and walking, from my temporary home to lectures took considerable energy out of me. I engaged in tertiary studies on and off in Sydney for about 10 years, in those latter years I bought a car.

Since my late teenage years, I felt very tired when I came home in the late afternoon and would want to sleep for at least half an hour, and at the weekend when I had the opportunity, I liked to nap after lunch; my stomach felt heavy. In the later years, the length of these sleeps increases considerably – I really feel that I need them.

At the age of about 30, a surgeon in Sydney successfully fused my right ankle. This has enabled me to walk without the heavy calliper since. I have better mobility. Just after, not because of, this I became an Australian citizen. I went to Canada for 18 months and boomeranged back; the prospect of having to walk on treacherous icy snow did not entertain my thoughts; also job prospects at that time were not the best in the Dominion for me.

Then I decided to enter the profession of high school teaching. Being a classroom teacher, I needed to be standing 4-6 hours a day. This put strain to the left (better) side of my body. Regular massage and attention to spinal structure were needed.

I got married, and my wife Wailin (Evelyn) and I have a daughter and a son. They grow up as well-adjusted persons. We had the luxury of having my mother kindly coming to Sydney for three months to help and adore the new addition each time we had a new baby. My wife works full time.

A cotton belt is tightened around my waist all the time since I was about 40 years old even when I am sleeping. This makes me feel comfortable. In later years, close to early morning, I may be woken up with a dry mouth due to breathing through my mouth and I feel that my abdomen is very relaxed. A sleep test negates sleep apnoea. A specialist suggests that this is caused by losing strength of the muscles in my abdomen.

For 21 years I taught full time and then because of some reasons and the “natural” decline of my physical strength, I took an early retirement on medical ground at the age of mid 50’s. As time went on, I had more tendency to fall – might be once or more often a fortnight. Occasionally, I employed a walking stick.

A couple of years later, one day in a shop, a lady came up to me and thrust a small pamphlet into my hand and said, “I think you have polio”. A few months later I found it among my pile of belongings. Out of curiosity, I rang the telephone number of Post-Polio

Network (NSW) Inc printed on it. Through the Network I have gained a lot of information on poliomyelitis and its late effects, and the medical support available. Subsequently, in Sydney, I was diagnosed (well over 50 years after the initial event) that I had contracted poliomyelitis when I was a baby. Physical examinations and muscular tests indicate the most likelihood of the case. Now I readily accept that it was the cause of my disability; and it answers a number of questions – for example, my weakness is not localised but spread over to different parts of my body; my body dislikes and shivers when there is a drop of ambient temperature; I have poor physical endurance and some other common symptoms of the late effects. Up to today, my mother is not convinced of the case. My conjecture is that I was affected by two illnesses (haemorrhoid and polio) concurrently or one after another at that early time of my life.

A very skillful podiatrist in Sydney has tailor-made insoles for my shoes – just joggers bought in the shops. This has increased greatly the comfort and ease of my walking.

Just over the age of 60 I was diagnosed with having severe osteoporosis and put under medical treatment although that I was not physically aware that I was suffering from it. This is believed to be the results of a lifestyle of lack of physical exercises and poor nutrition in early life. A couple of years later, my sore hip was identified as mildly suffering from osteoarthritis, very likely caused by the life-long unbalanced walking, and overuse of this hip. This problem is kept under control through nutritional supplements and hydrotherapy.

I continued to work part-time in a tertiary institution (2 to 3 mornings a week during semesters). This was not a physically demanding job.

At the age of 66, one night I stepped on a twig in the dark street and cracked the side of my poor right knee. I was hospitalised for 12 days, and recovered. Now I am 67 years of age and I am accompanied with a walking stick, which gives me a sense of security, although I can readily walk without it. With a slower walking pace and watchful eye, I seldom fall.

Since the last several years, the left (supposedly good) side of my body becomes weaker and is losing muscular mass and strength, faster than the normal ageing process I believe. I am enjoying a normal good health and follow a simple health-conscious lifestyle.

May 2004



Len Smith



My name is Leonard Kelton Smith and I was born at West Ryde on the 19th January, 1938. I lived with my parents and my younger sister Joan at number 20 Hay Street, West Ryde and this is my polio story as I remember it some sixty one years later.

It was on 4th June, 1945 when I was seven years old that I contracted the illness then known as “Infantile Paralysis”. I was in year 2 at “West Ryde Infants School” in Miss Farrell’s Class, when I took ill. I remember the afternoon well, as I developed a headache like I had never had before or since it was terrible, the pain was extreme.

I have included what I call historical comments in my story to give the reader an idea of how life was in 1945 as seen through the eyes of a seven year old boy.

Walking home from school that afternoon was difficult; luckily we did not live more than 10 minutes from the school. On reaching home Mum dosed me up with aspirin and sent me to bed. When there was no improvement the next morning she sent for Doctor Howe our local GP and Surgeon. This was not an easy task in 1945 as most houses did not have the telephone on and the nearest public phone was two blocks away on the corner of Moss and Adelaide Street. Doctor Howe's Surgery was just as far away on the corner of Endeavour Street and Victoria Road. You could not make an appointment like you can today you just presented yourself at the door and had your name entered in the book and took a seat in the waiting room. You could be there for 5 or 6 hours as Doctor Howe could be operating at Ryde Hospital until early afternoon before arriving back at his surgery and beginning to see that day's patients. How Mum contacted him that day I don't know but he eventually arrived at our house at about 7:00 pm that night. After checking all the normal things like temperature and listening to my chest, he had me sit up and raise my legs so that my knees were at their highest point. I was then asked to lean forward and touch my head on my knees. When I couldn't do this simple task he informed my parents that I had polio and would have to go to hospital that night.

The ambulance arrived about an hour later and I was taken to Camperdown Children's Hospital which for a small young boy was a long way from West Ryde and not easy for my parents to get to. They would have had a 15 minute walk to West Ryde railway station, a thirty minute ride on the train to Central and another 15 minute on a tram along Parramatta Rd to the Hospital. When you add waiting time to the journey it would have taken them over two hours each way.

I can remember the first few hours there to this day. I was taken to a small room and left on my own for a while before a doctor and a nurse came to check me out. When they had completed their examination I was asked to shrug my shoulders up to my ears and I was then given an injection. What it was I have no idea and as far as I can recall it was the only medication I ever received. I was then transferred to a general ward with all the other children suffering with polio. When I awoke on my first morning in hospital I found I was in a long room with about twelve beds on one side and nine on the other with the last three places taken up by large machine type boxes. I soon found out these were called "iron lungs" and were for children who could not breathe properly on their own. These machines were very noisy and I was glad I was not close to them. The nurse's station was just inside the doors at the top end of the ward near the iron lungs. There were two sets of double doors two thirds of the way down the ward; these opened on one side to an open verandah and on the other side to the bathrooms and a small closed-in verandah.

I was now told that I was to spend the next three weeks flat on my back and that I was not allowed to sit up or roll over or move in any way if possible. I could not have a pillow and all my meals had to be consumed lying down. How was I supposed to do this I wondered and I soon found out. Everything that we were given to eat at each meal came in a tea pot and you had to put the spout in your mouth and suck the contents down. It was not a very pleasant experience and I did not enjoy many of the things I was given. The worst thing was Bread & Butter Pudding which we were given every other night. It was terrible and there is nothing to this day that will make me eat or even try it. I can no longer recall what else we were fed on but I know I did enjoy the cocoa jugs each night. My next big shock was that there was no visitors allowed during the week; the only visiting day was Sunday for one hour in the afternoons and I began to look forward to seeing my mum and dad. So imagine my surprise when Sunday came around and the nurses began erecting a rope barrier down the centre of the ward. What's this for I asked the other children? Your visitors aren't allowed to come near you they said, and so it was that when visiting time came your parents had to stand behind a rope barrier and sing out to you across the space that separated you from them. I think it was as big a shock to them as it was to me that they

could not touch you or talk to you privately or give you any thing. This then was to be my life for the next few weeks. Was I upset? I suppose I was, it's too long ago now to remember. I had been in hospital before to have my tonsils out, so that it was not a new experience in itself, but no physical contact was.

At the end of the three weeks I was allowed to move and sit up again. The ward I was in had verandahs along three sides as I previously noted. In the fourth week I was allowed to have my bed outside on the enclosed one during the day which was good as I now could see what was going on around me rather than the ceiling and the four walls of the inner ward. I also started to have physiotherapy in the form of water bath exercises each day. We had some older boys in our ward, about 12 or 13 I guess, who were allowed out of bed and used to wander around and talk to us. I was a bit envious of them and the fact that they slept on the verandah and I asked if I could too. One day these boys moved my cot along the verandah until it was up near where the exhaust pipes from the iron lungs came out through the wall. This was to be a big mistake on my part for the roar of the machines was deafening and I couldn't wait to be moved again. Sleeping on the verandah in the middle of winter wasn't much fun either. There were canvas blinds that came down to the railings but the railings were an open grid type that let the cold night air and the wind in. When the blinds were raised in the mornings, you could look out across a big open lawn area to buildings on the other side. We would often see people wheeling trolleys along the far side of this area covered all over with a white sheet. The older boys told us that they taking the bodies of people who had died in the night to the morgue. I don't know if this was true or not but as a seven year old I believed them at the time.

During my fifth week at Camperdown the physio decided that I might need a brace for my left leg as this was my most affected limb and so I was measured up for one. I had to learn to be a ballet dancer as part of my exercise programme with lessons in standing on the tips of my toes like you see the ballerinas do. All of these exercise programmes must have worked for by the time I was ready to leave hospital it was decided that I didn't need the brace after all.

My last week in hospital saw me spend a night sleeping on the floor when they experienced a shortage of beds for the new arrivals and then for the next few days after that, my bed consisted of four wooden chairs, several planks and a horse hair mattress. I left Camperdown after six weeks on the day the Governor General, his wife, and the Duke and Duchess of York were to pay us a visit. We all received new quilt covers for our beds that day and although my parents and my uncle Horton, who was the only family member we had who owned a car, didn't pick me up until late in the afternoon, I missed their arrival in our ward. I was most disappointed at the time as I thought it was a big deal then. The ride home in uncle's car was a highlight of my life that day as it was the first time I had travelled along Victoria Road from the City and I could not believe that we had to cross so many bridges that I didn't know existed until then and this more than made up for missing the Duke and Duchess. It was to be another 10 or more years before I was to travel all that way again.

My routine now I was home was to continue doing the exercises in the bath and the ballet steps and to visit a specialist doctor who had his practice in Victoria Road just up the hill from Bowden Street towards Ryde Police Station and Courthouse. His house was two stories high and painted white and I remember these details because it was the first freestanding two storey house I had ever been too. The specialist said that I could go back to school on the 30th July and so mum took me back that day with the doctor's note, but Miss Brooks the Headmistress of the Infant School refused to take me back. She said I would have to have another month off as I was still contaminated as far as she and I suppose the Education Department were concerned at that time.

I finally returned to school on the 10th September 1945 at the end of the August/September School Holidays. What a shock I was to get for all my school books had been burnt and I found that for a few minutes I had forgotten how to write properly however as the day progressed I soon got back into the swing of things. Before becoming ill I had come top of the class in Miss Farrell's weekly tests most weeks but I now found myself near the bottom which was only to be expected I suppose having missed three months.

I of course now considered myself cured of polio and that my life would be completely normal but this was not entirely true. I suffered for the next 16 years with what I called my polio ache. During the winter months or when there was the chance of rain in the air I would develop this dull aching pain behind my left knee. The only way I could get to sleep of a night was to wrap my knee up in a large woollen scarf or something similar to keep it warm. I finally became free of this pain after I went to live in Papua New Guinea in 1961, where it is never cold even at night; this pain has come back again as I grow older but fortunately not to the same extent as before. Another weakness which as I got older I put down to the polio was a lack of strength in my legs when bush walking. I could keep up with my friends or even set the pace while walking along level ground but as soon as we came to any sort of reasonable hill or climb my leg muscles would go weak on me and I would soon find myself falling behind. Dancing was another activity which I found difficult and still do. I don't know why but my leg muscles do not like dancing and soon begin to ache behind the knees when ever I try.

In 2001 I first heard of the Post-Polio Network and was given some of its booklets to read which I did. I felt at the time that this did not apply to me and put them to one side. However in 2005 I began to experience a lot of pain in my leg muscles that would not go away even after a good night's sleep and I re-read the Network's booklet and began to see that some of the things in it did apply to me. I then paid my local GP a visit taking the booklet with me and, showing him the page of typical symptoms, said that's how I feel what can you do to help. He was sympathetic but explained that in all his years as a GP he had only ever experienced one other patient who had had polio and that he knew next to nothing about post-polio syndrome and was afraid he could do little for me other than prescribe a stronger type of painkiller. I tried these and although they did ease the pain they gave me an even worse problem in that they kept me awake all night. I went back and complained about this and he changed them to another type and suggested that I take them in the morning instead of at night but this did not work either.

I now decided to join the Network and find out what if anything other people did about their condition. Since coming in contact with other Polio victims I have learnt that maybe other things I had put down to injury or aging may be traced back to Post Polio Syndrome, for example, the back condition that I have suffered with since I was 33 years old and which I used to aggravate every time I used a small hydraulic crane which I had to pump up with my left leg may be because my spine was also affected by polio. My spine collapses to the left when I do heavy work and I have had my physio comment that no matter how many times she straightened it as soon as she let go it would collapse again. Is this PPS? Last week at the AGM people talked about weakness in their upper limbs which was never diagnosed at the time and from which I have always suffered. Can this also be attributed to PPS? In conclusion I want to thank all of the members of the PPS Committee for their wonderful work in bringing us a lifeline with so much help and information to help improve not just mine but all PPS sufferers' lives.

Just recently I received in the mail some brochures which listed reasons for belonging to the Network and I would like to conclude by saying that I find them just right for people of all ages.

29 November 2006

Polio Australia - A National Voice For Polio Survivors

On Wednesday 6 August 2008 a very historic teleconference took place involving representatives of each of the State Post-Polio Networks. Those present were Arthur Dobson (Tas), Tessa Jupp (WA), Trevor Jessop (SA), Frances Porter (Qld), Mary-ann Liethof (Vic) and Gillian Thomas and Neil von Schill (NSW).

The first motion adopted the final draft of the Constitution for Polio Australia which we have been working on for over twelve months. The nominees who will represent the States on the Polio Australia Management Committee for the first term were then declared. The nominees were Gillian Thomas and Neil von Schill (NSW), Arthur Dobson and Billie Thow (Tas), Maria Harding and Trevor Jessop (SA), Tessa Jupp and Jenny Jones (WA), and Frances Porter (Qld). The nominees were then elected to the inaugural Management Committee of Polio Australia. Mary-ann Liethof (Vic) will be an observer on the Committee while Victorian organisational representation is decided.

Finally it was resolved that Gillian Thomas be authorised to apply for the incorporation of Polio Australia and in so doing become its initial Public Officer. The appropriate documentation and fee were forwarded to the NSW Department of Fair Trading. As this *Network News* went to press we learned that incorporation has been granted. The Management Committee of Polio Australia will shortly hold its first official meeting at which the Office Bearers will be elected for the next two years. We are currently working on a revised funding submission for the new national body which will be taken to Canberra in September and discussed with relevant politicians and funding bodies. An update on Polio Australia activities will be given in the next *Network News*.

GST and Cars Purchased by Eligible People with Disabilities

I am grateful to member Zarrer Janjua for reminding me of this concession available from the Australian Taxation Office (ATO) which is not generally known in the community. The following information is drawn from the ATO website <www.ato.gov.au>. The relevant ATO publication is NAT 4325 and you can read the full version online or order a copy by phoning 1300 720 092.

You are eligible to purchase a car GST-free if you are an eligible person with a disability and you intend to use the car for your personal transportation to or from gainful employment (*you undertake paid work or work in your own business for at least eight hours a week on a regular basis, and the payment you receive is appropriate for your age, experience and capabilities*) for a period of two years or until you use the car to travel 40,000 kilometres from the date you purchase it.

You are an eligible person with a disability if you have a current disability certificate, issued by Health For Industry (HFI), part of the Health Services Australia Group, certifying that you have lost the use of one or more limbs to such an extent that you are unable to use public transport. You can only obtain a disability certificate from HFI. To do so you will need to phone the ATO on 13 28 66 or 1300 661 542 to obtain an *Application for medical assessment to obtain a car or car parts GST-free* (NAT 3417), which includes a *Medical Report on Applicant* form, have the form completed by your treating doctor or specialist, then send the completed form to HFI including any relevant medical reports and a cheque to cover the HFI assessment fee (currently \$135). HFI may issue you with a temporary or permanent certificate if they determine that you have lost the use of one or more limbs to the extent that you're unable to use public transport.

If you receive a permanent certificate, you will generally not need another medical assessment when purchasing a subsequent car GST-free. However, you will need to keep this certificate as it is required whenever you purchase a car or car part GST-free.

Post-Polio Network Office Co-ordinator's Report

**Ground Floor
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1 Fennell Street
Parramatta NSW 2151**

**Phone: (02) 9890 0946
Email: office@post-polionetwork.org.au**

Office Hours
Monday to Friday
10:00 am – 3:30 pm

General Correspondence / Payments
PO Box 2799 North Parramatta NSW 1750

Management Committee Matters
PO Box 888 Kensington NSW 1465



**George Laszuk
Office Co-ordinator**

Greetings from the staff and volunteers at Parramatta.

Since our last *Network News* we have had a few changes of staff in the office and we plan on making a few more in the near future.

Michael Lee who is one of our members has recently joined us in the office as a volunteer. Michael recently retired from the workforce and has excellent computer skills; he is a welcome asset to our office.

Another very recent recruit to our team is Natalie Millerd, who is joining us as a volunteer job trainee – in other words, she is undertaking a work experience placement. Natalie is 18 years old and was referred from a recruitment service called Jobmatch which is a division of The Northcott Society; we welcome her to the team.

Our last change is a mixed blessing. Carlie O'Reilly, our Administration Assistant, is going on maternity leave in a few months. Yes, that's right, Carlie is going to have a baby in March, for which we congratulate her and wish her the very best with her new baby. Carlie has been with us for two years and has done an excellent job. She will be dearly missed and we hope she will return to us during 2009.

On pages 19 and 20 of this *Network News* we present the first of a new regular feature on *Helpful Resources* (which, as Gillian wrote in her report, is taking the place of the *Information Bulletin*). In the first issue I wrote of train travel and I would like to expand on this.

A few months ago I was invited by RailCorp to witness a demonstration of an evacuation plan to assist people with a disability to disembark a train if it breaks down between stations. Basically the way it works is that each station has an unassembled platform on wheels which transports light equipment including a wheelchair. When a train has a major breakdown the nearest station with one of these platforms assembles one and places it on the tracks and as it is battery powered it doesn't rely on electricity to move down the line. When it reaches the train, the person is transferred to the platform and taken to the nearest railway station where arrangements can be made to get the person to his/her destination.

As far as I know this is only happening in the metropolitan area and I don't know how long it will take to implement the equipment to all these stations. I felt this service was worth mentioning for all you train travellers like myself.

The office has been very busy for the last couple of months, processing subscription renewals and preparing our financial year accounting records for the auditor. On the subject of subscriptions we are yet to receive a lot of renewals, so if you haven't renewed your membership yet please send your cheque or money order as soon as you can. Please remember that with your financial support we produce this newsletter and provide many other services to our members; without it you wouldn't be reading this *Network News*.

On the subject of money we received a payment of \$200 that was paid directly into our account. This transfer came from a Teachers Credit Union account on 23 July 2008. We are very grateful for your money but we don't know to whom to credit it. So please own up and ring the Office and stop our accounting staff from going crazy!

I would like to again acknowledge the financial assistance from the Lions Clubs in NSW, so far this year they have been able raise \$7,500 for our organisation.

Finally, below please find for your information our current office roster.

PPN OFFICE ROSTER	
GEORGE	Monday, Wednesday and Thursday 10:30 am – 3:30 pm
RAY	Monday 10:30 am – 3:30 pm
MICHAEL	Monday 10:30 am – 3:30 pm
NOLA	Tuesday 10:30 am – 3:30 pm
CARLIE	Tuesday, Wednesday and Friday 10:00 am – 3:00 pm
NATALIE	Wednesday 10:00 am – 3:00 pm
SHYLIE	Wednesday and Thursday 10:00 am – 3:00 pm

Helpful Resources

George Laszuk

This is the first instalment in a new regular series of Helpful Resources aimed at bringing you information about services and products that you might not otherwise be aware of.

Accessible Train Travel

A few months ago I had the opportunity to travel from Sydney to Queanbeyan by train and was pleasantly surprised. I use an electric wheelchair and up until now it has been a major hassle transferring from my chair to the train seat. Now Country Link offer a service which is quite comfortable for people in my situation.

I am able to remain in my chair and with the assistance of a portable ramp I can enter the carriage where there is a designated area for wheelchairs, very similar to the ones found in accessible buses but larger. There is a fold-down table available and even a power point next to your chair in case you have charge your chair; in my case it was useful for providing power to my laptop computer. Your seat is also located right next door to the accessible toilet for your personal convenience needs.

The staff are very friendly and obliging and when it comes to meal times they will take your order and bring it back to your seat, all you have to do is pay for it.

For more information on train travel in NSW ring Country Link on 13 22 32. Naturally, I can't vouch for services in other states.

Expo in Dubbo

On the subject of travelling, I will be going by train to Dubbo on 17 October 2008, where I will be attending an event called "Carers Anybody Anytime Expo".

Carers of all ages from across the region are invited to come together in one place, to be informed on issues affecting them, to link in with services and to make new friends. This event will be held in The Dubbo Civic Centre, Darling Street, Dubbo from 12:00 pm to 6:00 pm and admission is free. For more information call the working party on 1800 052 222.

TARS – The Aged Care Rights Service

TARS is a specialist community legal centre providing advocacy in NSW for the residents of Commonwealth subsidised Nursing Homes, Hostels, Retirement Villages and recipients of Community Aged Care Packages and EACH (Extended Aged Care in the Home) packages. TARS can provide specialised information, advice and support to help with choices, rights and complaints. All TARS services are FREE of charge.

To contact TARS:

Phone: (02) 9281 3600

Fax: (02) 9281 3672

NSW Country Callers: 1800 424 079

Address: Level 4, 418A Elizabeth Street, Surry Hills NSW 2010

Office Hours: Monday to Friday, 9:00 am – 4:30 pm

Email: tars@tars.com.au

Website: www.tars.com.au

Safe Bath

Safety Bath is a walk in, sit down type bath/spa specifically designed for mobility impaired people which can be fitted anywhere in the home.

There are types that are commonly used in homes: these are the Supreme, the Classic, the Avalon, the So-Lo and the Nova.

These baths combine the comfort and most importantly the safety needed to allow you to maintain your independence at home for many years.

Safe Baths can be fitted into an existing shower, an existing bath area or freestanding anywhere in your home.

To contact Safe Bath:

Phone: 1800 505 712

Address: Suite 48/90 Mona Vale Road, Mona Vale NSW 2103

Email: info@safebath.com.au

Web: www.safebath.com.au

I hope these items are of interest and some use to you. If you know of any resources that might be useful for members please contact the Office and we will publish them in the next Network News.

Support Group News

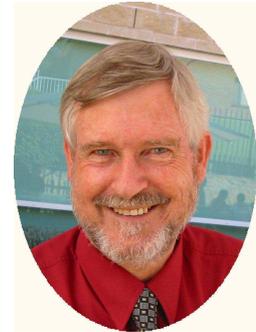
Neil von Schill

Support Group Co-ordinator

Phone: (02) 6025 6169

Fax: (02) 6025 5194

Email: support@post-polionetwork.org.au



As I indicated in my last report, through my involvement with the Physical Disability Council of NSW, we have designed 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.

Many Support Groups throughout the state have assisted greatly in this venture. In addition to taking the survey to **Albury/Wodonga, Wagga Wagga, the Northern Rivers and the ACT Groups**, the survey was also presented at our **June Seminar** and I was then able to make a very enjoyable visit to our friends in the **Hunter Group**. My thanks go to **Barbara McCormack** and **Barry and Wendy Chaff** for their hospitality and assistance.

May I express my sincere thanks to all members who have assisted by completing the survey. Many of you filled out the questionnaire at meetings while some took them home and posted them back. There was also a significant number of people both polio survivors and members of other disability groups who filled in the survey on-line. There has been in excess of **500 surveys** completed which has exceeded all expectations. Responses are now being collated and analysed and we hope to have a report and recommendations out by October.

On 13 October, Polio Network Victoria's Polio Officer, **Mary-ann Liethof**, will be travelling to **Albury** for a major **Polio Day**. In the morning session Mary-ann will present her impressions of her Churchill Fellowship visit to the US and Canada in April/May 2008. After lunch, allied health professionals and disability service providers will conduct interactive sessions with participants.

Congratulations go to the **Wagga Wagga Support Group** which was successful in attracting \$1,000 in funding from the Department of Ageing and Disability to provide transport to bring all their members to the Polio Day in Albury. We also expect a large contingent to travel from **Wangaratta** and surrounding areas. If members in these areas have not yet returned their Registration Form and payment they are encouraged to do so immediately.

If there are any members living in the **Greater Tamworth Area** who are interested in re-forming a Support Group in the Tamworth area they are asked to contact me. Similarly if you are living in an area not serviced by a Support Group and you are keen to see one formed then I would love to hear from you.

Finally, included with this newsletter is a **survey** prepared by Management Committee member, Rebecca Phillips. **We are reviewing our Support Group structure** and are keen to know how we can provide a service which better meets the needs of members as we experience decreased mobility and increased disability. Please assist Rebecca by giving us your thoughts and returning the survey to me at the address given on the form.

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.



Bread, milk, polio jab ... all in a morning's shop

This was the headline of an article by Tom Robbins in the UK *Observer* (27/7/08). He reported that the British supermarket chain Sainsbury's has aroused controversy by setting up travel clinics in 21 of its stores. Here shoppers can consult nurses for free and receive injections at prices that are significantly cheaper than those charged by specialist travel clinics. A combined diphtheria-tetanus-polio injection costs £20 at Sainsbury's compared with £31 at a clinic. The head of professional services at Sainsbury's says: *We will provide an efficient, good value one-stop-shop for people's travel needs – from a first aid kit to immunisations.* If the new clinics are successful they will be opened in Sainsbury's stores throughout the UK. *However some medical professionals are voicing concerns, arguing that travel medical advice is too complicated to be sold alongside baked beans and bananas.*

New wimpy polio virus

In 2002 Dr Eckard Wimmer and his research team caused a stir when they manufactured the polio virus from scratch by stringing together the chemical 'letters' of its genetic code. Fears were expressed that this technology could be used by bioterrorists. Patrick Barry, in *Science News* (26/6/08), reported that Wimmer and his colleagues are now using this technology to produce a new extremely weak polio virus by 'misspelling' the genetic code of the virus that causes polio so that the virus still reproduced but did so a thousand times slower than normal. The new weakened version of the virus when injected into mice trains their immune systems to fight off the real polio virus. *Many vaccines contain weakened versions of viruses. Currently, scientists make these crippled viruses by letting the normal viruses reproduce in cells in the lab until they randomly develop mutations that make them less virulent. But the approach is time-consuming and imprecise.* Another disadvantage of this method is that very occasionally these less virulent viruses mutate back to their deadly form so that a person can contract polio from the live polio (Sabin) vaccine. In producing the new virus Wimmer has used what he calls a 'death by a thousand cuts' approach. *By introducing hundreds of small differences in the viruses' genetic code, the new approach makes it very difficult for viruses to revert to their dangerous form.* The research is in its early stages. The new polio virus is not yet wimpy enough. About one in eight mice who received it died. However the rest of mice show signs of immunity to the non-wimpy polio viruses that infected us.

The Hospital Poems

Jim Ferris, Professor of Disability Studies at the University of Toledo, Ohio, won the American 2004 *Main Street Rag Poetry Book Award* for his book *The Hospital Poems*. Ferris was born with one leg shorter than the other. The poems are a memoir of the hospitalisations and numerous surgeries he underwent as a child. They describe many of the experiences of polio patients. He describes being *Orphaned for the first time / at five – no one died – / Mom took me to the hospital / And left. At once I was waif / and ward ... /*

until our bodies are corrected, / until the gods deign to let us go, / we are children of no one. In the poem For His Own Good Ferris contemplates his mother's feelings: ... I wonder / what it must have / been like to / give your baby / to the doctors. / What do you / tell yourself? / What do you / tell the brave / little soldier? Medical rounds when you doff your clothes and listen for a clue about what lies ahead will bring back memories of professionals, lords of the hospital, cold-eyed / white coats trained to find your flaws, focus on failings, / who measure your meat minutely. You are a specimen / for study, a toy, a puzzle – they speak to each other as if / you are unconscious. The poem Standard Operating Procedure tells how to conduct orthopaedic surgery: ... Bust a chuck / of bone the rest of the way out; chisel it if you have / to ... He won't remember much; kids are like animals / that way ... Tears and pain are standard operating / procedure, and you have other problems now to solve.

There is a moving foreword to the book by disability historian and polio survivor Paul Longmore. He wrote that Ferris's memories will remind people with many types of disabilities of *the psychic anguish, the personal costliness, of a program that aimed to refashion a boy into something he never was and never would become, that instructed him he would never be a whole and real person without radical intervention to alter him. Some readers will remember how the most well-intentioned of medical treatments pathologized their very being.* People without disabilities will also have experienced much of what Ferris describes: *The child's sense of being at the mercy of all-powerful adults who impose their will for the child's own good and are often wrong. The camaraderie of children against adult power ... Adult obtuseness in assuming that children have no true sense of dignity and can feel no sense of humiliation. The realization that one must submit to being made over in order to be regarded as acceptable, which is to say, human and loved. The resistance to all of this, the struggle to define oneself, to develop a sense of pride.*

Unfortunately the book no longer seems to be in print but second-hand copies are available on Amazon.com.

Polio killed Blessed Pier Giorgio

July saw a week of celebrations in Sydney for World Youth Day. Pope Benedict and hundreds of thousands of pilgrims visited the city. A coffin containing the remains of Blessed Pier Giorgio Frassati was brought from Italy to St Mary's Cathedral in Sydney where it was a focal point for pilgrims. The title 'blessed' means that Pier Giorgio is well on the way to being canonised a saint. He was born into a wealthy Turin family and was handsome, athletic and intelligent. He spent much of his time helping the poor and worked for social reforms. He died aged 24 in 1925. What caught my attention was that one of the many newspaper reports of his visit to Sydney attributed his death to polio. A search of the web revealed occasional brief and sometimes contradictory accounts of his illness. Most of the writers had little understanding of the disease. When the polio was mentioned its cause was invariably attributed to the poor and sick whom he had helped. One account said that he came down with a very bad cold which got worse. Pier Giorgio's grandmother was dying at the time and it seems to have been several days before anyone realised how ill he was. When they did realise *his illness was too advanced for anyone to treat.* There was talk of a flight to Paris to collect *anti-polio serum* but a storm prevented the flight and he died the next day. His sister who wrote a book about his life felt his death was indirectly caused by his parents' inattention and neglect during his illness. He is said to have become paralysed and died within 5-7 days. In the last day or so his mother would allow no visitors even the Archbishop of Turin to visit him. Just before his death Pier Giorgio is said to have written a note with his paralysed hand (or nearly paralysed hand in one account) with instructions to a friend who was helping in his work with the poor. Pier Giorgio was brought to Sydney to inspire young pilgrims that a normal young man can do extraordinary things. If only the cause of his death from polio had also been publicised to encourage vaccination!

Polio's patron saint

When researching the above story I was astonished to find, after over half a century as a polio survivor, that there is a saint who is designated the patron saint connected with polio. She is St Margaret Mary Alacoque, a French nun and mystic who lived from 1647-1690. She is listed on a number of websites that sell medals for patron saints of this or that. On some sites St Margaret Mary is listed as the patron saint against polio so presumably she is expected to protect against infection. Other sites list her as the patron saint of polio patients so if you do catch polio she may still help you. The stories of her life vary but they all include Margaret Mary being bedridden for a long period in her childhood. One version said that she had paralysis for six years as a result of rheumatic fever. Another said she had polio. In both scenarios she was healed by a vision of the Virgin Mary.

Low vaccination rates result in diseases' return

Unvaccinated people may ultimately live shorter not longer lives argues an article in the August 2008 issue of the American Journal *Popular Mechanics* by Glenn Harlan Reynolds. Measles which used to infect between 3 and 4 million Americans a year and cause 400-500 deaths was declared eradicated in the US in 2000 *except for imported cases. But that caveat is important. [Recently] an unvaccinated 7-year-old from San Diego became infected with measles while traveling with his family in Switzerland and ended up transmitting the disease back home to two siblings, five schoolmates and four other children in the doctor's office – all of them unvaccinated.* A San Francisco school which favours alternative medicine recently closed after 16 pupils developed whooping cough; fewer than half the children in the school were vaccinated.

The article explores why parents refuse to vaccinate. *Many are skeptical of modern science and medicine in general. (And it is true that most vaccines carry exceedingly tiny – but real – risks of serious illness or even death). But I think most are responding to a widespread belief that vaccines are linked to autism. Recent studies have soundly dispelled that notion. And a simple glance at health statistics shows that autism cases continued to rise even after thimerosal, the mercury-based preservative widely blamed for the supposed autism link, was largely phased out of US vaccines by 2001.*

Many opposed to vaccination say it should be a personal choice; if you want to be protected get vaccinated. The problem with this view is that *while the measles vaccine protects virtually everyone who is inoculated, not all vaccines have the same success rate.* Even if a vaccine is say effective for 90% of those who receive it the other 10% will not be at risk if most people around them are immune as it will be very difficult for the disease to spread. *When people decide to forgo vaccination, they threaten the entire system. They increase their own risk and the risk of those in the community, including babies too young to be vaccinated and people with immune systems impaired by disease or chemotherapy. They are freeriding on the willingness of others to be vaccinated.*

The current complacency is largely the result of the success of modern vaccines. *In previous generations, when epidemic diseases swept through schools and neighborhoods, it was easy to persuade parents that the small risks associated with vaccination were worth it. We quickly forget dangers. After the terrible 1911 Triangle Shirtwaist factory fire in New York there was a period of tightened regulations, followed by a gradual slackening of oversight until the next accident. The author asks what can we do? To some extent we have to do what the reformers of the 19th and 20th centuries did: Hector people about the importance of paying attention to our society's upkeep. Alas, our main allies in persuasion will probably be the epidemics and disasters that take place when too few pay attention.*

Power failure kills woman in iron lung

Several years ago I told the story of an American, Dianne Odell, who had been using an iron lung since she contracted polio aged 3, three years before the vaccine was available. In May, Dianne then aged 61 died because a power failure shut down her iron lung. According to CBS News, Dianne's family *were unable to get an emergency generator working*. Her brother said, *We did everything we could do but we couldn't keep her breathing. Dianne had gotten a lot weaker over the past several months and she just didn't have the strength to keep going*. Dianne earned a high school diploma, took college courses and wrote a children's book with her voice-activated computer.

Polio lab apes languish in post-Soviet limbo

Sukhumi by the Black Sea is the capital of the breakaway province of Abkhazia in Georgia. The province is not recognized by any country and is subject to an economic blockade by Georgia. Sukhumi houses the former pride of Soviet science, the Institute of Experimental Pathology and Therapy. Outside there is a battered monument featuring a baboon and bearing the inscription, *Polio, yellow fever, typhus, encephalitis, hepatitis and many other human diseases were eradicated thanks to tests on primates*. There were once 2,500 monkeys at the Institute. In the 1950s-60s the oral (Sabin) polio vaccine was produced and trialled at the Institute with US scientists before it was used on Americans. A Reuters report by Dmitry Solovyov (28/7/08) recalled the separatist war of the 1990s when both Georgian and separatist forces looted and some took away monkeys. A number returned dying monkeys. Today the Institute is a far cry from its *heyday, when academics, cosmonauts and Soviet statesmen mingled with the up to a million tourists who flocked to the institute each year*. After the polio trials the monkeys went on to become pioneers in the Soviet space program, orbiting the earth long before humans. Today *303 monkeys remain at the institute, many of them are old and dying. The bored survivors roam sullenly in empty enclosures, waiting to cajole an occasional morsel from one of the 25,000 visitors who come each year ... Abkhazia's cash-starved authorities cannot offer the financial support the Institute needs to haul itself back to the forefront of modern science*.



New Polio Orthotic Clinic to open in Sydney

I have recently received the following self-explanatory letter from Darren Pereira, Orthotic Consultant, Polio Services Victoria.

I would like inform the members of the Post-Polio Network (NSW) that I will be commencing a private polio orthotic clinic in Sydney. The orthotic clinic starts on 1 September 2008 and will be held at the Bone & Joint Clinic in North Parramatta [101 Victoria Road].

As you may be aware, I have been the orthotic consultant to Polio Services Victoria (PSV) for the past 10 years. During this period, I have provided orthotic assessment and treatment to over 1,200 Victorian clients who are experiencing the late effects of polio. I am also the Stance Control specialist in Australia and have successfully fitted 25 polio clients with Stance Control Knee Ankle Foot Orthoses.

The clinic, although only staffed by a single discipline, will be conducted in a similar manner to the PSV clinic. I will complete a thorough physical assessment and gait analysis and then offer clients an expert opinion on their possible orthotic management.

If a member from Polio-Network (NSW) would like an appointment in the Polio Orthotic Clinic, the reception team at the Bone & Joint Clinic will be more than happy to manage any enquiry on (02) 9890 7633.

It would be greatly appreciated if you could advise the Network's members of this new service and I look forward to meeting you in the near future.

Darren Pereira
Chief Prosthetist / Orthotist
www.neuromuscular-orthotics.com.au



I sought some more specific information from Darren and he wrote the following in reply.

At this stage, I will be commuting from Melbourne. The clinic will be initially held on a Monday and Tuesday, once a month (except the November clinic – see dates below), but if the response is good I would ideally like to hold it on the same days every fortnight.

The clinic dates have been set for the rest of this calendar year and they are as follows:

1st and 2nd September
13th and 14th October
31st October, 1st, 3rd and 4th November
15th and 16th December

As per the website, the Sydney consulting fee will be the same as the Melbourne fee [Ed – see below]. Unfortunately, prosthetics and orthotics do not get a rebate from Medicare and clients will therefore not be able to get a rebate. The reception team at the Bone & Joint Clinic will handle all payments and will issue a receipt from their company. A client is welcome to present that receipt to their private health insurer if applicable but my experience in Melbourne is that this also has not been covered. In regards to orthotic management, if a client would like me to provide an orthosis to them following my recommendation, I am more than happy to process an application through the PADP system for the client. As per their guidelines, however, I unfortunately will not be able to start an orthosis until formal written approval from PADP has been received. If a client wants to self-fund their orthosis, this can also be done.

In regards to parking, there are about 6 off-street parking spots at the rear of the Bone & Joint Clinic (entry off Wandsworth Street). There is also plenty of parking on Wandsworth Street itself. There is ramp access at the rear for clients utilising wheelchairs or scooters.

A Note About Fees (as described on)

Medicare does not currently pay for the cost of orthotic services. The Australian Government recently introduced the Enhanced Primary Care (EPC) program whereby a client with disability or chronic illness is eligible for 5 allied health interventions each year. Unfortunately, the Orthotic Profession has not been included on the EPC's list of approved allied health disciplines. The Australia Orthotic Prosthetic Association is currently negotiating with government to include the profession on the EPC list.

To ensure equity for the Prosthetic and Orthotic profession, the standard fee charged by Darren's service for a 30 minute consultation is the Medicare Schedule Fee (currently \$55.05) for Allied Health Professions. As Medicare does not cover the cost of orthotic services however, you will be financially responsible for all consultations including service provision, adjustments and minor repairs. If you have any queries with regards to payment, it is important that you ask about your financial responsibility.



2008 Post-Polio Network Seminar Program

<p><u>Now on</u> Saturday 6 September 2008</p>	<p>The "Tradies" Club 57 Manchester Road Gymea</p>	<p>The Baribunma Wheelchair See this revolutionary electric wheelchair (which can potentially return the freedom of the road to you) demonstrated by its designer Wally Bancroft Please note the changed date</p>
<p>Saturday 22 November 2008</p>	<p>Burwood RSL Club 96 Shaftesbury Road Burwood</p>	<p>Annual General Meeting and Seminar Mary-ann Liethof 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"</p>

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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.

Books etc (* indicates Post-Polio Network publication)	Size	Cost
<i>Managing Post-Polio: A Guide to Living and Aging Well with Post-Polio Syndrome</i> Second Edition 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.