

Jill's Jottings - Los Angeles

Footpath lack of Cross-Over's:

First thing that hit me was 'accessible contrasts'. I kept seeing Disability Aid shops and disability rights information describing how to lodge complaints if access was inadequate, but on the other hand I saw 50% of foot path crossovers were cliff hangers causing me (and Mary-ann) frequent anxious moments while I wheeled along the road for varying distances until I could again mount the footpath.

Richard Daggart and PPS Support Groups:

I was impressed by our host Richard's ability to fit such an active lifestyle around living with a tracheostomy and 24 hrs care services. Richard has a minivan adapted with side ramp and sliding door and a device that locks his wheelchair /portable ventilator in the front passenger position. I also learnt from Richard the difference between CPAP (continuous air pressure, so harder for weak muscles to breath out) and BiPAP (2 air pressures, 1 softer for breathing out that does not tire weak muscles so much).

Rancho Los Amigos and Orange County PPS support groups have similar issues such as the need to focus on pacing activities. 'Choose your battles' was a phrase I picked up. Support group members said many GPs still have no knowledge of correct PPS management, but at least they have access to two Los Angeles medical facilities skilled in PPS issues who can provide assistance and advise their GPs.

My manual Wheelchair:

Bringing my light weight manual wheelchair was a good decision. Mary-ann is a great help pushing me around airports and visits, and the wheelchair doubles as walking frame and luggage carrier. I am also experimenting with ways to minimize shoulder stress such as using my left leg to supplement wheeling, works especially well going backwards. I've bought a light folding (\$31.00 USD) walking stick to give me two sticks for walking. Most aids in the shop seemed similar to Australian prices, but wider selection. Scooters and wheelchairs seemed about 30% cheaper.

Airport staff seem to be more familiar with wheelchair s i.e. recognising my wheelchair has removable wheels. Mary-ann wheels me to the plane, then staff stow the wheelchair and return it to the plane door on arrival.

Rancho Los Amigos:

This is a huge Rehabilitation facility with a wide range of assessment, treatment and mobility skills. Most impressed by their Seat Pressure Mapping which results are projected on screen. Saw a Screen Key Board that selects letters by holding the pointer over a character and can learn its user's words. Saw a wheelchair 'joystick' hooked to computer controls and a Voice activated computer 85% accurate for the cost of \$200 USA. Ref: Wireless controls info X-10.com (Radio Shack) and Home automation Smart Home go to

Although Rancho has a 'Model House' which displays a range of familiar aids plus technological that controls house appliances via plug in activators to remote control functions, there does not seem to be an Aids Display such as Yooralla's 'Independent Living Centre' in Melbourne.

Rancho PPS Clinic staff are Dr, Nurse, OT, PT, Orthotist, with access to i.e. Psychologist, Speech Therapist, etc. Rancho's focus is detailed Muscle Strength testing to target useful exercise, avoid weak muscles damage from exercise and indicate function level to be achieved. Usual danger signals of 'stop before getting tired or feeling pain' were often referred to, likewise 'Listen to your body' so recovery with No Pain is achieved. Rancho prescribes home exercise programs rather than refer to local exercise program to avoid 'trainer/therapists' altering the exercise regime and teach Polio's to explain their needs and avoid being put into harmful situations.

Initial assessment lasts 2 hrs. Polio/PPS diagnosis made from Asymmetrical muscle strength, what a person could do at their peak and what now, i.e. look for a pattern of illness, recovery, PPS decline. Did PT have difficulty keeping up with other children is another pointer to earlier polio infection. Pain best treated by Pacing lifestyle activities, not medication. Rancho's PPS Guru Dr. Perry has done a lot of research on Polio walking patterns. Rancho tries to include family members to help them understand and support PPS needs. Rancho considers PPS similar to accelerated ageing, and warns that muscle contractures can start as early as 4-14 days if not treated while a Polio is confined to bed.

University of California Los Angeles:

UCLA is a huge medical facility that also treats PPS. The PPS clinic now describes itself as a Centre without walls because it arose after multidisciplinary team funding was removed. They have changed from in-house treatment teams to involving local medical services. To minimize local Treating Health Professionals changing UCLA's advice, they stress the need for Individual (not Group) programs as all PPS are different and teach PPS folk to understand and explain PPS issues to others - know what they can do and what not to do.

UCLA finds offering a free lunch to Medical Students to attend PPS lectures increases attendance.

Jill Pickering

Jill's Jottings - St. Louis

Post Polio Health International:

It was very encouraging to hear how Post Polio Health International started from the dream of one very pro-active and forward thinking person. Amazing to see how the drive of these early founders achieved so much - see Mary-ann's report for PPI activities now. Also scanned PPI book shelves and found several useful reference books, don't know any of you folk reading this report have come across them;

- 'Sick and Tired of Feeling Sick and Tired by Paul J. Donoghue, PhD and Mary E. Siegel PhD
- 'The Survivor Personality' by AL Siebert, PhD
- Acknowledgement – Opening To The Grief of Unacceptable Loss by Peter Leech, MSW, LCSW and Zeva Singer, MA, MFCC

Paraquad Inc. - St. Louis:

This organisation was most impressive with its wide range of services and client focus philosophy. Interestingly their Carers are hired by and work for the client, not PQ the Org. i.e. clients interview, select and instruct their own carers, who can be family, friends or strangers, but not spouses. Paraquad Inc. St. Louis manages carer payments via Government funding and monitors Carer services every 3 and 12 months to ensure its correct running.

The philosophy of Paraquad St. Louis includes; Systems advocacy, Removing barriers, Creating opportunities, Providing a State Presence to Lobby Health Services, and Training folk to Self-Advocate.

I was pleased to hear of their Health and Well being Programs, Mobility Focus, assessments, recycling Mobility Aids and repairs. Including a varied program to assess/train handling Mobility scooters and wheelchairs.

Interested to hear how their 'Quality Assurance Program' had been adapted to enhance the Personal Attendance program by developing very practical 'policy and procedures' such as, measurement tools, Needs Assessments, Review of Mental Health needs, Information teams etc.

Paraquad Inc. St. Louis also has Developmental Programs which involve 18 PQSL Case Managers with qualifications ranging from Social Work, Psychology and people with disability knowledge/experience.

Jill Pickering

Jill's Jottings - Warm Springs (70 min drive South of Atlanta)

Departing from St. Louis was more pedantic, security took awhile and all looked very severe, but I made it OK, minus my one third bottle of tap water. Wheelchair survived OK, into the shuttle bus and then a fantastic run in the Convertible Car Mary-ann arranged. Never been in a car with the roof back before, luckily warm weather. Found road signs confusing, which was a problem as I was 'Navigator'. Arrived Warm Springs OK. My room had a walk in shower and 2 styles of shower seat, great arrangement.

Really enjoyed having virtually all doors (generous width) opened automatically, also several KMs of concrete paths to wheel along in the forest (bush). No steep gradients, except the one Mary-ann had to hold me back on; in hindsight we should have taken the lift. So enjoyed scooting up the hill with my loaned scooter, per Mary-ann's notes.

I felt very at home in the old style multidisciplinary/interdisciplinary team approach and the hands on care staff take. Vocational Rehab participants are called Students, and the original complex was designed by FDR (Franklin Roosevelt) to be like a university campus. FDR was ahead of his time in many ways for treatment settings. Students is a valid name when you consider all the services described by Mary-ann. Loved the old style orthotics department, still have staff who know the art of old style brace materials, a service much sought after by older PPS Americans and I'm sure by many Australian polio's. They also have developed imaginative skills in adapting wheelchair s and mobility scooters.

When let loose on the borrowed scooter, I headed straight for the forest wheelchair tracks, saw deer and squirrels and took so many turns I nearly got lost... Also enjoyed sitting by their lake which is used to hold disabled sport competitions and Paralympics team practice areas. Also watched several duck families enjoying the evening quiet.

Had great horse ride on 'Prince' (see photo section) safe and well managed riding area, first time on a western saddle, and used the folding travel right stirrup cup I made in Los Angeles (see photos), all went well. Enjoyed the drive there and back in the Convertible hire car - what an experience...

To bed early as have to catch 9am flight tomorrow to Washington DC.

Jill Pickering

Jill's Jottings – Washington DC (Part-A)

We are staying in a University for deaf/partial hearing students. Interesting, as I do not understand sign language. So far we've learnt words like 'thank-you' and 'you are welcome' and carry a pen and paper for other inquiries. My room's door 'bell' flashes a strobe red light in the room, no sound. Also the bedside clock has huge numbers so I don't need glasses to read it.

I am in a disabled room which is well fitted out, and many doors slide open or have wheel chair push buttons. Unfortunately for Mary-ann the terrain is very hilly. All shuttle busses are fitted with wheelchair ramps and run to the local underground Union metro station. The metro is wheelchair accessible, but has a 4 inch gap b/w platform and train wheelchair entrance which is of concern as my front wheelchair wheels are only 1.25 inches wide and can easily slip between.

My afternoon was quite an adventure; I headed off on the shuttle and was dropped at the Museum of Natural History, "downtown". Wandered along footpaths for a while, but due to building works did not get far. Looked through the Natural History Museum which was very interesting and well laid out. Time came to ring the driver to return, so I found a phone, and someone to explain its use. The driver said he'd pick me up in 20 minutes. After waiting 40 minutes and time getting late I headed to the closest metro station and with help purchased my first metro ticket. Trains ran about every 10-15 mins so before long I was at Union Station. Took me 20 minutes to locate the University shuttle bus stop as Union Station has at 3 different street access levels. In fact the station is enormous with numerous retail outlets, eating places, a post office, souvenir shops, etc., and is very like a substantial shopping complex. By now it was 7pm, but still light, as I sat in a back street on my own. Luckily after 15 minutes a few sign language students started gathering. Phew - at least I had the correct bus stop. At 7.45pm the shuttle arrived and I knocked on Mary-ann's door at 8pm! This was followed by a good meal at a new eating place Mary-ann had found on campus, since the other restaurant closed 7pm.

Sunday we caught the shuttle to Union Station, and then bought tickets for the sightseeing bus that has a 2 hr touring circuit and 25 stops to get off/on from over a 2 day period. All the circuit buses lowered the floor and extended a ramp, all Soooo easy. Had a 45 minute boat trip which was not accessible but OK for me to walk on and they carried my chair on. Mary-ann and I had different sights to see for the afternoon so hopped off the tour bus at different spots. I looked around the American Indian Museum and again found it well laid out for wheelchairs and information. Back to the University via the tour bus and shuttle service, this time reached Mary-ann by 7pm, so am getting more proficient. I am becoming more confident travelling in a wheelchair, but have to keep resting my shoulders to avoid neck pain.

Monday morning was a bit of a worry. As I was getting out of the bath, the fire alarms went off, while drying myself I heard loud speakers saying to exit the building. As I was dressing I heard a knock on the door, but when I reached it (having to transfer to my chair and still in underwear) found the corridor empty, but also smoke/fire free. By the time I finished dressing (10 mins after first alert), the show was over and Mary-ann arrived to see how I was.

Am spending the morning typing my jottings and now off to join Mary-ann at Union Station to then catch a taxi for lunch with the local Post Polio Support group. More on Washington jottings later.

Jill Pickering

Jill's Jottings – Washington DC (Part B)

Visited Dr Lauro Halstead at the National Rehabilitation Hospital, Washington DC

The clinic was begun by Dr. Lauro Halstead in the 1980's after he started experiencing new weakness that was puzzling doctors at the time. Clinic PPS numbers soon swelled, but are now slowing up. The clinic now only sees about 50 new patients a year, plus f/u visits on an as needs basis for PPS folk already assessed by the clinic.

The Post Polio Clinic team work closely together and conclude their assessment review by round table discussion with PPS team members, the patient and patient's 'significant other'.

First day - PT, OT and Doctor assessments in the morning. Afternoon is for other tests such as MRI, X-Ray, other allied health disciplines etc. The patient then overnights in 'hotel' style accommodation on site and returns to the clinic next day. The overnight 'time-out' is important as it gives patients time to absorb and reflect on the day's information, and to contact other family members to clarify early polio history or take measurements etc for future home modifications.

Second day - Provides time for additional questions that have arisen overnight and for further individual needs such as exercise programs, ADL, home modification etc.

The PT and OT staff share common treatment areas, with overlapping responsibilities. They have gait training equipment that will take a patient's full standing weight, on a stationary/moving platform. The mechanical leg walking facility can be strapped to someone with no/minimal movement leg movement to simulate walking patterns and avoid the need for a therapist to bend and manually move legs.

One impressive area is their Daily Living simulations. They have mock up street crossings, with traffic lights, curbs, shop fronts, 2/3 of an adapted car, as well the usual bedroom, bathroom/toilet and kitchen areas for assessment, practice and prescribing assistive devices. The adapted car has equipment that can show, for example reaction time from accelerator to break etc. Once a patient has adequate skill and control for driving on the mock-up car, they are assessed on the road by a qualified driving assessor.

This clinic also uses seat mapping technology in conjunction with other verbal and manual assessment to prescribe and confirm correct seating. We were told the orthotic department workshop was very small, but its services were frequently used.

Next day Mary-ann and I headed to the FDR Memorial by the river near 'Downtown'. I was impressed by its simple design and open spaces with samples from each of FDR's Presidential 4 terms in office. Mary-ann then did a great job pushing me for 30 mins into the central Mall area in hot conditions. We separated by a green shaded area where I ate my lunch leftovers. As I and other folk were crossing a busy street, a truck with flashing lights and siren blaring suddenly turned and we all scattered! Had pleasant time in the Air and Science Museum before heading back to Mary-ann at the University via Metro rail and shuttle bus. By now I am very proficient and arrived 'home' by 6.15pm. Tea at the student canteen, then bed. Ready for Johnstown, Pennsylvania.

Jill's Jottings – Johnstown

Short flight to Pittsburgh, then hopped into the car Mary-ann had booked. Luckily not a convertible as it rained nearly all the way through 2.5 hrs of traffic jams and roadwork's to Johnstown. Then, there at the motel, waiting for me, was a scooter very thoughtfully booked on loan via the John P Murtha Neuroscience and Pain Institute – so off we scooted looking for somewhere to eat.

Next am Sharon met us at the motel and walked us next door to the John P. Murtha Neuroscience and Pain Institute. A grand schedule had been organised for the day, starting with a Newspaper reporter and the institute's media person taking photos of us and Institute staff as we toured the premises. Then a series of staff came to explain their roles and how the clinic's activities fitted together. I am most impressed by the positive way staff interact here. Like Rancho Los Amigos, Los Angeles, the patient stays in one room while various team disciplines arrive to evaluate the patient's situation. There is also a great sense of the 'whole' person being viewed (physical, psychological and spiritual 'self'). This clinic is not afraid to discuss the sensitive issues of a person's weight, depression and spiritual (such as how they see their place in life, what drives them and where it is all going) as part of a person's total picture. This approach also seems to help people more readily accept the benefits of aids, modifications and scooter/wheelchair mobility issues, rather than the 'I'm not ready for that yet' approach sometimes taken. Two new approaches to PPS management trialled and found beneficial here are acupuncture and aroma therapy. The aroma therapy practiced here is based on herbal properties, not the aroma, to assist pain relief and muscle relaxation. The Therapist is careful to avoid herbal treatments that may aggravate other treatment/conditions the patient may have.

Being a Regional PPS clinic, staff will search the web to find services nearer the patient's home area to provide services such as; orthotics, allied health services, driving assessments etc. This clinic finds other services supportive of learning about Post Polio needs and how to best manage PPS. The whole atmosphere seemed very holistic, innovative and positive.

Early to bed after listening to such intense information. By now I am feeling in need of more 'catch-up' sleep. Late rise Saturday then sightseeing. The only way for me and scooter to reach Downtown Johnston was local bus (all accessible). I headed for a nearby bus stop and was glad the bus arrived 5 mins early as it was raining. The driver lowered the bus frame, then platform (by front door) then ramp. Total sequence took 60 secs. Once secured in the bus I asked to be dropped off at the Transit Centre. Looking aghast, the driver said I was to catch the next bus (5 mins later) as his Downtown trip took 50mins, not 20mins. I quickly said "no probs, I'd enjoy the tour" and the driver proceeded to tell me about suburbs we drove through. I joined Mary-ann for lunch at the top of the Inclined Plane from Johnstown, great view. Then off to meet Jan (PPS clinic), but the meeting place was further than I thought and the battery level looked risky. So a coffee/access to electricity was needed. This caused great excitement at the local 'Subway' as they had not served coffee before and the owner Nick had to think laterally to find a socket. After all this commotion people sitting nearby were all chatting together with Jan, Nick and I about scooter uses.

As I scooted back to the Transit Centre a passing bus sounded his horn, so I waved - it was my earlier bus driver. Then as I mounted the bus to go 'home' my friendly bus driver again appeared, secured my scooter and organised with the new bus driver to drop me off at my motel's front door - great service!

Early to bed to be ready for an early departure drive to Pittsburgh then flight to New York.

Jill Pickering

Jill's Jottings - New York (Part A)

Slight turbulence in the aircraft as we flew through clouds in front of severe weather crossing to our West. Nearly had a heart attack as I navigated the 8 inch plus gap between station platform and train.

After a quick unpack I went for a local wander but did not get far as the footpaths slope sideways more than I'd found before and the area is all up and down, plus rough footpath and road surfaces. However I did find a grog shop and what I thought was milk nearby, only to later discover the 'milk' was yoghurt - I had wondered why it cost three times the price I paid previously. Always something new to add to the tourist experience.

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

During the afternoon a chance for me to catch-up on the computer while Mary-ann has a local wander and writes post cards, a luxury she has not been afforded so far. Just as I felt all was flowing smoothly, I returned to the hotel 5pm after popping out, to find people gazing at a stationary elevator while staff rang for a mechanic. Fortunately no one was caught inside it. For the next few hours I watched people using the stairs for anything up to eight floors. Mary-ann came to the rescue at 6.30pm with a take away dinner and wine which we ate in the lobby, picnic style, while the mechanic completed his work. Soon after 7pm I entered my bedroom - and stayed there. We are on the 4th floor, a long way to crawl.

By now my neck/shoulder was sore from several days of wheeling so Mary-ann rubbed in Jan's 'Pain mix 1', which is her own mix of essential oils Sweet Marjoram, Lemongrass and Chamomile which she had made up just for me during the Johnstown visit. As a sceptic I was pleasantly surprised when 10 mins later I felt definite relief, less pain/discomfort, so straight to bed to make the most of the herbal brew – thanks Jan!

Tomorrow sightseeing and more adventures, no doubt.

Jill Pickering

Jill's Jottings – New York (Part B)

Tuesday saw improving weather. Mary-ann and I wandered through Central Park, about 3 blocks away, before I headed off to the Natural History Museum which offers a planetarium I wanted to investigate. Looked good - so I'll plan to see it when I visit the Special 'History of the Horse' display occurring over the weekend. Enjoyed slowly getting closer to Downtown New York by wheeling, walking and resting my wheelchair in great weather, also all down hill. I'd done some homework and knew bus 104 ran past our hotel, so hailed it 4.30pm for a ride home. Their lift and ramp seemed an older version of the type I'd recently used in Johnstown, but did the trick. Was secured in the bus and asked where I wanted to dismount. Then the bus soon became very crowded, but 30mins later the driver arrived to untie me and organise the lift/ramp – great service.

Interesting aside - safety awareness seems scarce, surprising in such a litigious society. We see bike riders without helmets, workers carrying large timbers without gloves, drilling holes without ear muffs or safety goggles, taxi drivers are not required to wear seat belts, wide gaps for public transport users (especially wheelchair s) to negotiate, rough footpaths, etc.

The pavements continue to slope sideways and at cross roads, such a nuisance! Home again, this time the lift working fine so dinner then bed.

Wednesday met Susan Fish and had lunch 'with a lake view' - see Mary-ann's notes. It was interesting to meet a Physical Therapist working as a private Physio with Post Polios. Susan learned the approach to managing PPS issues from her patients, a positive example of what we need in Australian PT's. I am becoming more and more convinced that PPS management is as much about our approach to new PPS challenges as it is about the physical aspects of managing pain, weakness, exercise and mobility issues. There is so much information here about management, aids and equipment, but still USA Post Polio sufferers hesitate to take advantage of modern technology available to assist them in daily Living Activities. I almost feel we should be able to design the concepts of a new program approach called i.e., "Harnessing PPS Demons to reach new achievement levels" – any comments from readers??

PS – Popped out for a local shop only to be tipped out of my manual wheelchair by a tiny 1 inch bump thanks to the latest road works to spring up. Now on my 3rd glass of red wine, settling nerves. I was only moving slowly, so don't know why it happened, except that I don't normally use my manual wheelchair outside, so suppose my foot path negotiating skills are low.

Looking forward to sightseeing adventures Friday and the coming New York weekend.

Jill Pickering

Jill's Jottings - NewYork (Part C)

Friday 15 May, So wet, but not such a problem when sightseeing from a bus in the dry! Unfortunately no good for photos. My first 'All accessible bus tour' had a malfunctioning wheelchair access ramp. Next one had a manual over-ride to allow me on. So stayed on this bus 1.5 hrs with water running down from the open top deck stairway beside my wheelchair location. Interesting seeing the sights of New York, but nothing that really caught my interest. Maybe it's all be different on a sunny day. Next bus also had malfunctioning wheelchair access, so this time I walked on.

Saturday, fine sunny day for touring, see Mary-ann's notes.

Sunday headed off to visit the NY Natural History Museum. Had a smooth ride on my now familiar 104 Metro-Bus to catch the touring bus. Hopped on a tour bus which had yet another malfunctioning ramp, then found my Museum stop was cancelled due to a New York Parade being held in nearby streets. Apparently at least one parade is held each weekend in NY. I ended up alternatively walking and pushing my trusty wheelchair a few blocks, and looking at the street stalls in streets along the parade route. These stalls were more than the usual airport tourist stuff. Really enjoyed the Museum visit as the 'package' I purchased included "Horses through the ages" and Planetarium plus IMAX 'live' Dinosaurs screenings.

The horse exhibition showed horse evolution from three to one toes, with digestive system, muscles and skeleton structure interactive displays, including a skeleton comparison of horse rearing and human to compare heights. The display also showed how far back in history man began domesticating the horse, and how the horse supported man's development.

The planetarium show was about earth's fiery start from two rocks colliding zillions of years ago with surface crust exploding and then coming together again as earth and the moon, all of which according to this show happened in 4 weeks. The show also showed how asteroids hitting the earth then and subsequently have both caused havoc and created life as we know it. The IMAX dinosaurs were like a short David Attenborough television program, but fascinating to see on a 3 dimension screen.

I finished the day browsing in the horse souvenir shop, plus buying horse souvenirs. Amazingly, as I crossed the road departing the Museum, who should tap me on the shoulder but MARY-ANN. With heart-felt thanks I accepted being pushed back to our hotel. I am beginning to look forward to getting back to my 'stable' of mobility scooters in Melbourne - USA street surfaces and road crossings are getting on my nerves. Partly as I'm not used to sightseeing in a manual wheelchair and partly from a lack of consistent road crossings and side paths, or smooth surfaces that makes it impossible to go far. Road works also force wheelchair users on the roads regularly!

Now settling down for typing, tea with Mary-ann, packing then bed ready for our trip to Framingham (near Boston) Monday AM.

Jill Pickering

Jill's Jottings – Framingham

Ok flight to Boston with an addition security check of having to put my wheelchair cushion through the X-ray machine. After shopping with Mary-ann at Wal-Mart, I ventured off alone. Usual scenario of footpaths with 50% missing crossovers, or just stopping dead at a main road. But weather was fine and I enjoyed pottering around.

The Spalding Post Polio team is very professional, cohesive and realistic about PPS issues. I was especially taken by their frequently verbalized acknowledgement of earlier Polio experiences making it hard for individuals to revisit 'Polio Demons' that occurred during the initial Polio experience. Their aim to empower PPS clients with knowledge about assistive devices and support programs while not being dictatorial is well balanced. They also have the benefit of a diverse range of therapists on the team so can take several different approaches to helping PPS clients come more readily to terms with what is now confronting them. I was personally very impressed with Bob, their Orthotist. He seemed ready to embrace new challenges with PPS clients, and had several PPS folk (who called themselves 'Guinea pigs' to trial new designs he keeps creating. This clinic feels one drawback of the 'E-Knee' is its weight which can be a problem for people trying to support the E Knee with surrounding weakened muscles.

Bob's approach has been to use flexible orthotic materials to give 'bounce' and utilize several pressure sensitive knee joints to allow up to 18 degrees knee flexion while weight bearing. Knee flexion degrees can be individually set by a screwdriver, so the client can control the level of knee muscle control they want to use/exercise. The person walks with a straight leg, but depending on the degrees of flexion set, can supplement the hinge with their own upper leg muscles. I'm feeling this could allow me to ride a horse with some knee flexion (essential when riding) and confidently weight bear through – knee stirrup. Unfortunately I did not get time to chat with Bob, but am buoyed by the possibility something may be available for me in the future.

Early evening for me to prepare for an early start for the airport and Toronto.

Jill Pickering

Jill's Jottings – Toronto

Canada still has inconsistent footpath crossovers, and even more sloping footpaths to limit the depth of snow settling on paths over winter. Again I tried the Toronto subway system. Started off fine, but ran into great difficulties when working my way up three levels at Union Station. First and second levels were fine, but could not get the lift on the 3rd level to open so pressed the operator assist button. After twice asking politely for help, with no result, I shouted to the operator - I need help please come to show me how to use this lift. A frustrated man then rushed up and explained I had to hold both buttons at the same time, and the bottom one for 30 seconds before the door would open. Mary-ann and I returned to this lift the next day and I was relived she also felt confused, particularly as the first instruction said press orange button... but no orange button existed... Finished off the experience with a spicy hot minestrone soup, and eventually found my way back to the 'not so accessible' hotel without having to use that lift again.

Jill Pickering

Jill's Jottings – Ottawa

I felt very privileged to meet personally with Marcia Falconer and her family during our 2 days in Ottawa. I have held Marcia in high esteem ever since I first heard her speak at a Sydney seminar organized by Gillian Thomas and the NSW Post Polio Support group. I was most interested to hear Marcia explain how parts of the polio virus can continue to exist as non-active fragments in the PPS spinal cord and her theories about how this can happen and its influence on general chronic inflammation levels found in many PPS folk. We are fortunate to have a champion such as Marcia with her scientific background and inquiring nature to research PPS issues in depth and in such a systematic manner. I feel the next 5 years will produce results that benefit others with post viral infection issues, as well as PPS folk.

I also loved the curry meal Marcia and David treated us to. A fitting conclusion to 6 weeks of travel Maryann and I shared. I always felt this trip was a great opportunity for PNV, Mary-ann and me personally, and I was not disappointed. Thanks again to all those who contributed to my finances.

In summary, I feel that although we did not find much new ground breaking information, we repeatedly saw viable styles of PPS Clinic delivery that echo our experience with Polio Services Victoria, but that also add dimensions of at least three PPS service delivery styles. Future Government lobbying about what is needed to support PPS service delivery is now well defined by the recent clinical experiences we can quote to sceptical Government bureaucrats.

Lastly, although Marcia kindly drove me to Ottawa Airport and saw me through the check-in process, it felt very strange not being with Mary-ann. Having had such a supportive, friendly and active travel companion for nearly 6 weeks, I missed her presence. But it won't be for long as after 5 weeks in GB I'll be back doing my usual one day a week at PNV with Mary-ann and swapping experiences over a Vietnamese lunch per usual.

Jill Pickering