

# The Winston Churchill Memorial Trust of Australia

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*To identify techniques to better manage  
the late effects of polio*



Los Angeles - Rancho Dr Jacquelin Perry, Mary-ann & Jill 25.4.08

**The following pages are the daily blog entries made by Mary-ann on her 6 week trip to North America in 2008. Her travelling companion was Jill Pickering, Polio Survivor and long time volunteer at Polio Network Victoria.**

## Los Angeles Monday 21 April 2008

Our 14 hour flight went without a hitch. On arrival at 7.30am local time, Jill was met by airport staff with a wheelchair and, because I was travelling with her, we were both 'fast-tracked' through customs – what a bonus! The staff member then proceeded to collect both our luggage and Jill's own fold-up wheelchair. We were apprehensive about getting out of there, but the last check point was just a cursory glance at our passports and we were on our way. No metal detectors – no taking off shoes – everyone helpful and friendly. Couldn't believe it!

Had a bit of a problem finding a taxi that would take Jill's wheelchair, though. We had no trouble loading it into a sedan on the way to the airport so neither would they, but what can you do? In any case, there was a man co-ordinating the proceedings and in a relatively short time, we were collected by a van. Jill had a bit of a struggle with the step up but managed to clamber aboard. Our contact in LA, Richard Daggett, had kindly booked our accommodation at a place called H.O.M.E. and had prepared detailed instructions on how to get there. That came in really handy for the taxi driver. The freeway system here is incredibly confusing and you really have to know where you're going.

So, we reached H.O.M.E., sweet home, which stands for "Housing Of Medical Emergencies" and is run by the Assistance League of Downey. It is a 10 unit apartment complex close to the Rancho Los Amigos National Rehabilitation Centre. According to their Mission Statement, the "Assistance League of Downey is a nonprofit organisation of volunteers who, in addition to their fundraising efforts, provide for and administer vital, quality services for people in need in the Downey area." The accommodation itself has a Spanish influence, is motel style and perfectly comfortable – certainly unbelievable value for the USD\$25.00 per night we are paying! It's not exactly the most conveniently located place if you want to see the sights or be close to shops, but it is near the rehab centre and that's where we have our appointments. Oh, and it's very quiet . . .

Richard Daggett is the President of the Polio Survivors Association and Editor of the Rancho Los Amigos Post-Polio Support Group Newsletter ([www.polioassociation.org](http://www.polioassociation.org)). He met us on arrival yesterday and offered to take us on a tour of the local area today. Richard contracted polio at the age of 13 and was in an iron lung for some time. He has severely limited muscle function, uses an electric wheelchair and has a tracheostomy for ventilatory support. However, in typical polio style, he is a very busy man, although he still found the time to pick us up in his fantastic, low floor, modified people mover driven by Nora, one of his 5 wonderful support workers. We cruised around the area, with Richard providing commentary on the historical use of the numerous abandoned and derelict Rancho Los Amigos buildings surrounding H.O.M.E. and the now upgraded rehab centre. Because of the earthquakes common to California, these older buildings did not meet the safety standards required for seismic activity. It was quite sad to see such amazing buildings lying vacant.

One small down-side of staying at H.O.M.E. is that it doesn't allow for internet access. Once again, Richard came to the rescue by taking us to his house which has wireless connection. We all chatted like old friends while I did what I had to do on the computer. He then took us to lunch at a quaint Italian restaurant, followed by a bit of a browse around the local shopping centre. Jill is keen to do some horse riding during this trip, but forgot to bring her modified foot stirrup. After a bit of thought, she decided to buy some twine which she could use to fashion into something suitable. After all that excitement, it was time to return H.O.M.E., so Richard dropped us off with the promise of some interesting revelations to be had at Rancho Los Amigos National Rehabilitation Centre tomorrow. So far so good . . .

## Los Angeles Tuesday 22 April 2008

Today we were greeted by the sound of a helicopter buzzing above our H.O.M.E. As we watched, the 'copter came in for a landing in the car park on the other side of our chain link fence. Now THAT was interesting . . . Just as we were wondering if we should be rushing inside and bolting the doors and windows, a large number of what we hoped were school children started rushing towards it. As no sounds of combat ensued, we assumed it was some kind of educational demonstration. Jill gazed longingly through the fence thinking that, even though it wasn't a horse, a ride on that helicopter might be a bit of fun.

Richard Daggett collected us at 11.00am for a look around the Rancho Los Amigos Rehab Center. Once again, we were provided with lunch, this time at the hospital canteen. Richard has really taken us under his wing and given us much more of his time than we had any right to expect. He introduced us to a number of people at the volunteer centre, one of whom had fond memories of visiting Australia (mainly Sydney) on a 5 day trip as a chaperon to half a dozen school children. I suggested she might enjoy it even more if she came for longer without the kids, to which she readily agreed! We then wandered over to see the general orthopedic and pulmonary clinics. Rancho is a large rehab hospital and there were numerous patients waiting for assessments and consultations. Interestingly, as well as the standard car accident cases, a number of spinal cord injuries treated at Rancho are caused by shootings among gang members. (You can see why we might have been a bit apprehensive about the helicopter incident.) For several decades, Rancho has had the services of Dr Jacqueline Perry, a brilliant orthopedic surgeon who later became the Head of the Polio Clinic. Dr Perry has had a hospital wing named after her and still does the occasional consultation at the age of 90. We didn't get to do any actual clinical observation today but will be attending a specific post-polio clinic on Friday, together with other scheduled appointments to view a range of management techniques and options available at Rancho.

Southern California boasts 13 polio support groups, each attracting an average of between 12 and 18 attendees at any given meeting. The Rancho Post-Polio Support Group is one of the larger ones and Richard sends out 700+ monthly newsletters to people around the area. Tomorrow we will be meeting with members of this support group for lunch (of course) at a Mexican restaurant. That should please Jill's penchant for chili.

One service worth mentioning is the very low cost (approx \$2.00) pick up and drop off 'taxi' service called "Access Services" run by the consolidated Transportation Services Agency (CTSA) for Los Angeles County. Access Services is responsible for the administration of Access Paratransit, the Americans with Disabilities Act (ADA) mandated paratransit transportation program for Los Angeles County and is committed to improving the mobility on public transit of persons with disabilities. Additionally, as the CTSA, Access Services is responsible for coordinating transportation programs of the various social service providers in the county. It is means tested for low income rehabilitation patients and takes people not only to and from hospital, but also for appointments and even social outings. Richard did mention, however, that there was the possibility of a bit of a wait. This service is across LA and is paid for by a 0.25% tax contribution. The other interesting practice they have in California (not sure yet about other parts of the country) are specific disability licence plates for cars. They still use stickers for temporary disability but for those with a permanent disability, plates are the go.

Back we went to Richard's house so I could hook in to his wireless internet system to upload the previous day's report and check emails. Once there, however, Richard started showing us a number of photo's and presentations he had on his computer – all of which were so fascinating that we totally lost track of time. One of these photos was of Richard shaking hands with Jonas Salk, whom he met in the 1980's. That was pretty impressive! By all accounts, he was a lovely man. If you haven't yet read

“Polio: An American Story” by David Oshinsky, it’s well worth trying to borrow/ordering from your library. It tracks the history of the American polio epidemics and the efforts made to produce an effective vaccine - focusing on Albert Sabin and Jonas Salk’s totally different philosophies and approach to the task.

By 6.30pm, it was way past Jill’s bed time and her energy levels were quite depleted. Surprisingly, Richard still showed no signs of flagging and offered to drive her the few blocks to H.O.M.E. while I got cracking on the internet. I finished at around 7.45pm and decided I had better let Richard get on with his own life while I got some exercise by walking. Richard assured me it was only a few blocks away and gave me specific instructions. Although it was becoming quite dark, I felt confident that I would be H.O.M.E. in no time, and promptly proceeded to get horribly lost. Unfortunately, I was also lugging my fully loaded briefcase and had on my nice, NEW sandals. My problem was that I had turned down the wrong street, knowing that something was off, but thinking that any minute now I’ll find another street that will take me in the right direction. This particular street, however, was made up of a number of dead-end courts and was long enough for me to develop a few choice blisters from my lovely shoes - so off they came. Eventually, I gritted my teeth, turned around and walked the length of the street back to where I had gone wrong. Not even a block further down was the actual corner Richard told me to turn . . . So, down the RIGHT street this time but by then it was very dark and I was a bit tired and emotional and couldn’t make out any landmarks at all. Richard to the rescue again! By phone, he gave me clear, calm instructions and within 5 minutes I was walking through the front door of H.O.M.E., safe and sound.

**Los Angeles**  
**Wednesday 23 April 2008**

Another sunny day greeted us, although we haven't been having particularly warm weather. More like a nice Autumnal day in Melbourne, staying around 19-21 degrees. Every so often I've been seeing humming birds hovering for a few moments, then darting off at full tilt. Never having seen one before, I was surprised at how tiny they are.

We were collected by Richard at 10.00am and driven a few miles away to 'County Orange' to meet up with 8 post polio support group members for lunch. Unfortunately, we'll be missing the real meeting on Saturday, because we fly on to St Louis that day. Our discussions were the same type of thing you would hear anywhere a group of polio's congregate. The issues concerning post polio syndrome are obviously fairly universal. However, I was asked a few thought provoking questions such as "What percentage of Australian polio survivors have pulmonary problems?" and "How many people were in an iron lung?, and "How many cases of bulbar polio were there?" Unfortunately, with Australia's appalling historical record keeping on the subject, I had no ready answers, although I assume some of this information is hiding away in dusty archives somewhere. I have not (knowingly) had a lot to do with polio's experiencing serious respiratory problems – that is to the point where ventilatory support is required both day and night. Of course, many people use CPAP machines at night to assist with sleep apnea. Although there has been some discussion here regarding the use of BiPAP. Where the CPAP provides positive pressure designed to keep the airways open, there is an argument suggesting that people with weakened breathing muscles, weakness of diaphragm, or scoliosis have difficulty actually breathing out against this pressure. The BiPAP is designed to give a certain pressure when breathing in and reduced pressure when breathing out. This may be something to discuss with your doctor during a future visit.

Our Mexican food was good and plentiful and we parted company knowing a little more than we did before lunch. After surviving my own version of "Lost" last night, I decided to visit a large office supplies store next door to buy myself a brief case on wheels. At least if it happens again, I'll have one less problem to deal with . . . We dropped off Jill on the way back to Richard's, where I uploaded my last exciting installment onto the website. I quickly checked emails as I didn't want to impose on Richard any longer than I had to. I don't want to get to the point where we wear out our welcome. It was nice to see an email from my colleague to say it was all a bit quiet without me. I chose to interpret that message to mean they were missing me . . . Whilst I was there, Richard gave me a copy of an excellent film to watch called "A fight to the finish". It is a 1 hour documentary tracking the history of polio in America using old footage, people's personal experiences, the March of Dimes, Roosevelt, and a segment on physiotherapy which featured Sister Elizabeth Kenny. Unfortunately, the copy I watched lost sound somewhere in the middle so I missed quite a bit of information. However, I'll see if Richard can provide another copy that I can take back to Australia. Even though it's American, there are many parallels that I'm sure people will appreciate.

I managed to walk back H.O.M.E. without getting lost and chatted with Jill about her impressions so far. She is doing a bit of doodling and will give me something to upload after each location which we will be calling "Jill's Jottings", so stay tuned.

Tomorrow we are off to visit Dr Susan Perlman at UCLA, together with Richard as our trusty chaperone. People I spoke with today were singing her praises so I'm really looking forward to our meeting. More in my next report.

**Los Angeles**  
**Thursday 24 April 2008**

I can't believe it's Thursday already! Today we met with Dr Susan Perlman, Clinical Professor of Neurology, Neurogenetics Clinic, UCLA Neurological Services and Melinda Guttry, Physiotherapist, UCLA Rehabilitation Services. This was the first in what will undoubtedly prove to be a series of fascinating taped interviews.

We started off with a light lunch at one of the hospital complex deli's during which time Dr Perlman relayed how she was originally introduced to post polio syndrome (PPS). Sometime during the mid-late 80's, a local support group brought in a wad of information with a request that UCLA's Neurology Clinic start up a specific Post Polio Clinic to service people on that side of town. The Rancho Los Amigos Hospital had been running a clinic for some time, but it was all the way across town (25 miles) and the numbers emerging at that time seemed to warrant an additional service. Luckily, Dr Perlman became interested enough in PPS to do more research on the various symptoms and had access to the full complement of supporting physicians including physiotherapist, Melinda Guttry. Over the years, with the general rationalisation of resources and the way the health insurance system is set up in America, these days much of the supporting therapeutic, aids and equipment services are mainly referred out to specific services. However, after 20+ years, Dr Perlman and Melinda Guttry have been able to network with and educate many professionals, such as orthotists, to a stage where they are confident that effective treatment and services will be provided for polio survivors. Dr Perlman is also very active on the professional speaker's circuit, as well as giving annual presentations on the latest research in PPS attended by the local post polio community. I'm sorry I'll be missing out on her May presentation because I believe they are excellent and accessible – both information-wise and physically.

Dr Perlman has also written numerous papers on the latest research being carried out in the area of PPS and believes the most exciting developments are in the areas of 'inflammatory markers' and the immune treatment 'intravenous immunoglobulin' (Ivlg). A 2002 study of Ivlg using Swedish polio survivors concluded that the results (relating to increased muscle strength) were promising, although they were not conclusive due to the low number of patients studied. Since then, more research projects have been undertaken and this will definitely be something to keep an eye on in future. Both Dr Perlman and Melinda Guttry were kind enough to allow me to film their response to a series of questions that were provided by members of the polio community. The resulting discussions will be of great interest once editing has taken place. I advised Dr Perlman that I would be providing copies of the edited tape compilation to all who participated. She seemed impressed with the scope of the study tour and the fact that I would be sharing the information with as many members of the polio community as possible. Dr Perlman believe that it is vital for polio survivors to become self-educated regarding PPS, then to educate their own health service providers. After all, that's how she got started in the first place.

On the way back to the car park – which we were able to use free of charge thanks to Richard's disability licence plate – Jill and Richard decided to have a race. There is definitely something to be said about electric motors . . . We were taken on a bit of a tour of Beverly Hills and Hollywood, along Sunset Boulevard. Didn't catch sight of any 'stars' but saw some interesting scenes nonetheless.

And for anyone who thinks I'm on a holiday here, tomorrow we have a full day at Rancho Los Amigos starting at 8.30am and finishing at 5.00pm. Just as well I love my job!

## Los Angeles Friday 25 April 2008

With an 8.30am start, today was jam packed with interesting things to do at Rancho Los Amigos Medical Complex. We started off meeting with Jan Furumasu, a physical therapy instructor working in the Seating Centre. The majority of people being seen at the Seating Centre would be those with spinal cord injury but they do see polio survivors on a regular enough basis to be familiar with the issues of finding an appropriate chair and cushion. They had cupboards full of different types of cushions, and a 'seat mapping' sensor pad that Jill tried out to see how it worked. This is particularly important for people with a spinal cord injury who are unable to feel the type of pressure that could potentially cause an ulcer. Polio survivors are simply able to identify the pain and rearrange themselves. However, it was very interesting to see the variety of chairs and cushions available.

We then moved on to meet with Molly Doyle, the Program Director for the Centre for Applied Rehabilitation Technology (C.A.R.T.) who in turn introduced us to Occupational Therapist, Kathleen Shanfield. Kathleen showed us a range of assistive devices for working on computers. Although I'm sure we have similar technology in Australia, I was amazed at the range of keyboard and mouse/toggle options available, as well as the voice activation software and physical support such as armrests. She then took us over to the model house which demonstrates a range of assistive technology to enable individuals with disabilities to live independently. The beauty of C.A.R.T. is that it's all located in a 'house' on the hospital grounds.

Then we were off again for our next appointment to meet with Dr Jacquelin Perry who introduced us to her innovation, the Pathokinesiology Laboratory, which deals with instrumented diagnosis of complex gait dysfunction and the definition of disability. As mentioned in my report on Tuesday 22 April, Dr Perry is a living legend at Rancho Los Amigos and is widely acclaimed as an expert in the area of orthopedics and rehabilitation for polio survivors – both professionally and by the polio community. It was a true privilege to be able to spend time with Dr Perry and learn about her 50+ years experience at Rancho and the methods she developed for working with polio survivors. She is still very passionate about her work, consulting at the age of 90. She has also had the added challenge of living with Parkinson's disease over the last decade or so. Dr Perry consults for the post polio clinics run at Rancho every Friday and is still seeing ageing polio's she operated on when they were children. For example, she performed a spinal fusion on Richard Daggett when he was just a teenager. With the passing years, they have both developed a great deal of respect for each other's contribution to the polio community.

After lunch at the hospital canteen, we were introduced to Dr Sophia Chun who now heads up the post polio clinical team made up of an orthopedic specialist, physiotherapist, occupational therapist and nurse. Each new clinical assessment can take up to 2 hours. They see around 20 polio's per clinic, of which 3-4 are new assessments. People are referred to the Rancho post polio clinic from all over America, so any referrals for the additional respiratory, speech therapy, dietary or psychological services that may be required are usually directed to local service providers. However, Dr Chun made a point of saying that those physicians/health workers should be knowledgeable about post polio syndrome and/or be willing to communicate with the Rancho post polio team. Their particular focus is on muscle function and overuse of particular muscle groups. Dr Chun cited a protein experiment done with polio's that was successful in improving muscle function in the short term, but eventually left people weaker a few days on – simply because they had then proceeded to overwork those newly 'strengthened' muscle groups. As the sign off to one of her articles, Dr Perry wrote "Be an 'Intelligent Hypochondriac' – Listen to your body and adopt a program that avoids the strain." In other words . . . PACE!

It was really interesting to sit in on an evaluation for one of the polio patients where all the team members sat in a group to discuss their various findings with a view to working out the best way to assist that person.

I was able to videotape discussions with Drs Perry and Chun which will be add to the information provided on the previous day by Dr Perlman. They were also very taken with my project and wanted to receive a copy of the tape and report. It was interesting to note the difference in approach by the neurologist vs physiatrist but there was no doubt that all techniques used were of benefit to their polio patients.

I later went back to Richard Daggett's house and filmed him discussing the social and financial impact of post polio on him and his community – a different angle again. We enjoyed a farewell dinner and said our goodbyes to our new friend, Richard. We were very fortunate to have had him as our contact in LA and left feeling that we had achieved far more than our expectations.

So farewell to Los Angeles for tomorrow – St Louis, Missouri – here we come!

## **St Louis**

### **Saturday 26 April 2008**

Although our flight wasn't leaving until 11.30am, our taxi driver asked to pick us up at 7.45am because she had another booking at 9.00am. I can tell you that, after such a full schedule, I was ready for a lay in. Maybe tomorrow . . . In any case, it was just as well we went a bit earlier because there were so many people, it was difficult to know what was going on. Once again, Jill's wheelchair went some way towards expediting our trip to the book-in counter and before long I was sitting in the departure lounge with a croissant and coffee for breakfast.

We boarded an American Airlines flight and headed west. By the time we were coming in over St Louis, we caught refreshing glimpses of green grass and trees everywhere – so different from LA, which wasn't very different from Melbourne insofar as the 'big dry' was concerned. Because of the 2 hour time difference, we landed at around 5.00pm after a 3 ½ hour flight. A relatively short taxi ride and we were at the very comfortable Hampton Inn & Suites. Unfortunately, not at the \$25 per night rate of H.O.M.E.

Our St Louis contact, Joan Headley – Director of Post-Polio Health International, met us at the hotel and took us cruising in search of a good Italian meal. They have an area here that seems to feature Italian restaurants but being Saturday night, most had up to a one hour waiting list. We eventually found a hotel restaurant that served excellent Italian cuisine and I enjoyed one of the best risotto's I've ever had. I can only assume it had about 1 million kJ's because it was so good. Jill had a seafood 'soup' which was pasta and seafood (curiously no liquid) but must have been good because there was nothing left. Joan also had a risotto which she said was delicious – so all good. What was not so good was that our conversation was cut short when a small band set up shop and proceeded to serenade the diners. Actually, by that stage, the area we were in had reverted to a bar – including the smoking crowd, so we beat a hasty retreat.

Joan then took us on a night tour of down town St Louis which looks quite lovely and I'm keen to see it tomorrow in the daylight. There are many old buildings and a huge symbolic arch which represents the 'Gateway to the West' (I think – Joan told me but I forgot!). Apparently you can actually ride up the arch, so that sounds like a good Sunday thing to do. This arch is positioned near the river separating Missouri from Illinois and the river is currently lapping over some parts of the road due to rain and snow melt.

We now have internet access in the rooms, so I can upload to the website to my heart's content.

Tomorrow we tour St Louis city.

## **St Louis**

### **Sunday 27 April 2008**

Well, I started off with good intentions of 'touring St Louis' but by the time I woke up and muddled around doing 'stuff', it was lunch time. Jill and I decided to catch a taxi to the Gateway Arch to see what it was all about. It is an amazing structure completed in 1965, made of stainless steel and located in the Jefferson National Expansion Memorial park. You can ride up to the top in a 5 person pod they call a "tram". It's not good if you're claustrophobic but it only takes 4 minutes to get to the top, which would be a problem if you didn't have a head for heights as it's 192m or 630ft high. However, you do get a cracking good view! Directly below is the historic Old Courthouse which is renowned for a ruling passed on Dred Scott, a slave who asked for his freedom but was ultimately denied. There also just happened to be a big baseball game on, so that made for an interesting photo of the stadium. Unfortunately, there are a number of steps up here and down there to get to the trams, so Jill wasn't able to see the view. So while I was up the top, she went to see a documentary on the building of the Gateway Arch and wandered around the museum.

By time we left, it had started to drizzle slightly so we found a taxi to take back to the hotel where we had about 45 minutes to 'relax' before heading downtown again to a cocktail party that Joan Headley had arranged in our honour. Our hosts were Art and Gayla Hoffman who have a lovely 'condo' on the 14th floor filled with interesting artwork and boasting gorgeous views across various parts of St Louis. We were joined by Dr Martin Wice, a Psychiatrist (rehabilitation specialist) who sits on the Board of Post Polio Health International; Penny, a previous Member of the Board; and Joan's brother, Jim and his wife Judy. It was a very civilised way to spend the evening and we really appreciated the effort people went to on our behalf.

Tomorrow we have an 'official' meeting with Joan Headley at Post Polio Health International ([www.post-polio.org](http://www.post-polio.org)) which I plan to video, before meeting with a team at Paraquad Independent Living Center. It will be very interesting to compare services.

**St Louis**  
**Monday 28 April 2008**

We arrived at Post-Polio Health International (PHI) at 9.30am where we met with the Director, Joan Headley and Brian, a brand new staff member. I'm sure his first day proved to be as effective an orientation to PHI as it was for us. I set up the video and taped my interview with Joan as she discussed the service and the various research projects they have funded. PHI is an information resource for polio survivors, their families and the health care community. It actively promotes networking between survivors, professional communities and assistive equipment manufactures. PHI also publishes a quarterly newsletter, compiles the Post-Polio Directory listing post-polio health resources and polio support groups around the world, and maintains a website: [www.post-polio.org](http://www.post-polio.org) that averages 50,000 hits per month.

Fortunately, Joan is also on the Board of Paraquad Inc., a Center for Independent Living: [www.paraquad.org](http://www.paraquad.org). As such, she was able to set up a meeting and tour of the facility for the afternoon. There are hundreds of Centers for Independent Living in the USA and approx 22 of those are in Missouri. We met with a number of key workers who each discussed their respective programs. Paraquad Inc. has been going for 37+ years and has an impressive range of services that are truly consumer driven. They employ around 120 staff with a mandatory 50% having some form of disability. Unlike ParaQuad Vic, they also have clients with sensory and cognitive problems and are also looking to expand into mental health. They have considered changing the name "Paraquad Inc." but have such a significant reputation in the state, it's difficult to 're-brand'.

We were very impressed with the layout of the facility, with every area being totally accessible to wheelchairs, assistive devices everywhere – including a really neat visual telephone system for deaf workers so they can sign their conversation. Even the kitchens were well thought out, with benches that you can wheel chairs under and an easy load dishwasher. Paraquad Inc. also employs 2 support workers to assist any staff members who may require it. Programs include: Accessible Housing; Advocacy; Assistive Technology Access; Benefits Planning Assistance and Outreach; Breast Healthcare Education Program; Career Options and Employment; College for Living; Consumer Directed Services (enabling people with physical disabilities to live in their own homes by training them to hire and manage personal attendants); Deaf and Hard of Hearing; DEAF Way Interpreting Services; Enabling Mobility Center; Independent Living; Information and Referral; Peer Consultation; Public Policy; Youth and Education; and my very favourite – Recycled Durable Medical Equipment. To quote from their brochure, this last one "is a one-stop clearinghouse providing information and resources, assistance identifying needed durable medical equipment, repair or restoration of donated medical equipment and the distribution of recycled or used equipment". Equipment is donated, sanitized, repaired (if needed), and sold on for approx 25-30% of the cost of new equipment, including a 90 day guarantee. Depending on the persons' income, they can make repayments as little as \$5.00 per week until paid off – or if the individual is in dire straits or even homeless, Paraquad Inc. may decide to provide the equipment free of charge. Any profits go right back into the program.

During our discussions, we also learned that the Consumer Director Services included the capacity for people to nominate a family member (not the spouse) or friend to provide basic care. The rate of pay for this care is approx \$8.00 per hour. 50% of consumers choose a family member or friend, and a survey of 100 of their 600+ clients revealed that satisfaction levels rated highest for family, then friends, then 'strangers' (professional support workers).

Paraquad Inc. also has a strong relationship with Washington University (Missouri campus) and has many health-related students assisting in areas such as occupational therapy and research. There was so much to see in the "Enabling Mobility Center" – again, quoting from the brochure – which "is a joint program between Paraquad and Washington University, providing information, training and community demonstrations on assistive technology to persons with disabilities, their families,

independent living specialists, healthcare professionals, researchers, engineers, vendors and the general public.” Suffice to say we were mightily impressed!

Joan then offered to drive us around to see an area called “Forest Park” which is close by, but by then I was on information overload and needed a rest. Instead, I put down this report! However, we did go out for a lovely meal to finish the visit, which probably added another 3kg to my ever expanding waist-line!

Tomorrow we’re off again to visit Warm Springs, out of Atlanta, Georgia. So stay tuned . . .

## Atlanta/Warm Spring Tuesday 29 April 2008

Off to the airport this morning to visit another town in another city. It's hard to believe we've already been here for more than a week. We've been kept so occupied with interesting people, places and things (and food!), there's been no time to think of how the time has been passing. Fortunately, this was only a relatively short flight at just over an hour in a 'puddle jumper'. While Jill was waiting for her wheelchair to be brought up from the hold, I thought I'd capture the moment (see photo).

Apparently the weather is uncharacteristically cool in Atlanta and Warm Springs at the moment, although we have fresh, clear air. At the airport, we hopped aboard a shuttle – well, I 'hopped' and Jill 'hoped' to board with it's 3 nice, big steps – which took us the car rental place. I had booked this online and decided to splash out and get a convertible! I figure you have to do something a bit special every now and then . . . And I've never driven one before – let alone on the other side of the road. The car is a Chrysler Sebring and initially we had trouble with get the car to actually 'convert', but eventually figured out that was because the guy who had so kindly put our all our luggage and Jill's wheelchair in the boot hadn't factored on the mechanics of the roof opening and closing. So out it all came, then some other guys repacked everything into the back seat and – voila – we had our convertible. OK, I admit that it's not very practical but it sure looks cool. So off we went, with the wind in our hair, listening to R & B on the radio and feeling like "Thelma and Louise" (without the tragic ending . . .). The reality was that my hair was whipping my eyes and face to shreds, all that clear air was a little TOO fresh, and the surrounding freeway traffic noise drowned out any music. Warm Springs is a little over one hour's drive South of Atlanta and eventually the traffic lessened and I was able to pull over and get my cap and jacket out of the back seat. That made all the difference and we continued on our glamorous way.

We made it to the Warm Springs Institute for Rehabilitation at around 5.00pm and found we had taken a step back in time. It's a stately, rambling complex full of history and character. We were settled in to rooms in Kress Hall which was built in 1934 as dormitory housing for polio patients. These rooms have since been converted to 'motel style' accommodation and can now be rented to families of patients and students, as well as conference guests. Kress Hall has a charming common lounge room with a verandah looking out over the lovely gardens surrounding the various buildings. This would be a very pleasant place to sit in warmer weather. The Executive Director of the facility, Greg Schmiege, was kind enough to offer us the use of these rooms free of charge – yet another example of how hospitable and accommodating people have been during our visit. We will be meeting with Greg tomorrow for an orientation of the place and suggestions of what to do and who to see over the next couple of days.

Just a bit further down the walkway are located 17 bronze busts known as "The Polio Hall of Fame", sculptured by Edmond R Amateis, and depicting 15 scientists and 2 laymen who were instrumental in the fight against polio. This information and much more, is in a brochure that enables visitors to do a self-guided tour of the facility. I'm hoping for the guided tour which takes place each week day. There is also an exhibition to see classified as the "Smithsonian at Roosevelt Warm Springs: Whatever Happened to Polio?" which is on loan from the Smithsonian's National Museum of American History. And, of course, we want to see Roosevelt's Little White House, which is located a mile or so down the road.

We drove into the township of Warm Springs looking for something to eat at around 6.30pm and just managed to catch a meal before the place closed at 7.00pm. We each had a delicious chicken salad, the remains of which Jill took back in a 'box' for lunch or another night's tea. As the meals are usually so generous, everyone is offered foam boxes for leftovers here – it makes for quite a cost effective way of eating. One problem that we have noticed is that the Warm Springs area has notoriously bad cell (mobile) phone reception which makes it difficult to keep in touch.

Tomorrow beckons with so much to do, so little time!

## Atlanta/Warm Springs Wednesday 30 April 2008

As promised, Greg Schmieg, the Executive Director of Roosevelt Warm Springs Institute for Rehabilitation ([www.rooseveltrehab.org](http://www.rooseveltrehab.org)) met us bright and early to discuss our orientation of the complex. This began with a guided tour by Linda Creekbaum and Mike Shadix, the Librarian and historian for Warm Springs. Between the two of them, we heard many stories about the people who passed through and the history of the buildings. For example, a number of years ago, all the old wooden columns needed to be replaced with hardier concrete at a cost of \$1,000 each. Through a bit of creative promotion, they received money from a variety of sources including numerous previous polio patients. Each column that was funded bears a plaque with a short inscription, i.e. Donated by Better Carter-Wright "Where life began, again." and John A. Swearingen – August, 1962 June, 1966 – "Here I learned to love." We were also told that funding had been received from Rotary International's Polio Plus Program for the 17 bronze busts known as "The Polio Hall of Fame" to be joined by a number of other prominent, more contemporary people involved in the ongoing eradication of polio and that plaques would be mounted to explain each person's endeavours. At the moment, if you were not aware of your polio vaccine-related history, you would be none the wiser. We continued to make our way around the quadrangle to an area that had been used for walking practice. It had various steps, undulations and surfaces to negotiate. I later saw photos and a film on how this was put to use and was glad I hadn't had to do it.

Then it was time to view the "Smithsonian at Roosevelt Warm Springs: Whatever Happened to Polio?" exhibition. There was a sign above the door reading "Contagious Entrance". Apparently, many school children passing coming along to see the exhibition refused to pass though because they thought they would catch polio. The static display depicted the nature of the virus, the various treatments, vaccine development, and Franklin D Roosevelt's (FDR) part in it all. Of course, what would a polio exhibition be without an iron lung, so a photo was duly taken.

By then it was time for lunch and Greg had a special treat in store for us. Mike was invited to join us and we also met up with Physiatrist (physical rehabilitation specialist), Dr W Burton McDaniel, Jr, who has worked with a number of post-polio patients and consults at Warm Springs. So the 5 of us piled in to Greg's car for a mercifully short drive to an 'all you can eat' restaurant called "The Bullock House", where they serve good ole' Southern cookin'. Of course, I had to try Southern fried chicken, fried green tomatoes, corn bread and something called "Brunswick Stew" which is a mix of minced meats and corn kernels. All this was washed down with "sweet tea", an iced drink that certainly lived up to its name. I am SO going to have to diet when I get home . . .

In the afternoon, Greg became our tour guide for a look at the facilities Warm Springs is now involved with. In 1974, the State of Georgia took over the operation of what had previously been run by the Georgia Warm Springs Foundation. It became a medical rehabilitation facility specialising in brain injury, spinal cord injury, orthopedic and stroke rehabilitation, as well as other general rehabilitation services.

Today services include: Medical Services; Long Term Acute Care; Inpatient Rehabilitation; and Outpatient Services such as, Acupuncture, Aquatic Programs, Diabetic Foot Center, Post-Polio Services, Rehabilitation Technology, Seating and Wheeled Mobility Clinic, and Wound Care. Warm Springs also has an extensive Vocational Rehabilitation Unit, Therapeutic Recreation & Fitness, the totally accessible Camp Dream, and Conference Services. As a matter of fact, Warm Springs will be the location of a major, international post-polio conference in April 2009 being put together by Joan Headley at Post-Polio Health International. They are expecting around 400 participants. I wonder if I could get another grant . . .

With so many impressive facilities on site, we really had to think about what we wanted to see the most. Greg took us to the rehabilitation services area where we were met by Rene James, Physical Therapist, and Sonal Nakrani, Occupational Therapist. Rene explained the very 'hands on' approach Warm Springs has to physical therapy and that, although they may not have the range of high-tech equipment that private hospitals can afford, their time tested "Roosevelt Way", together with interdisciplinary teamwork, yielded very effective results.

Next on the list was the newly opened "Blanchard Hall" where all the outpatient services are provided. After Rancho Los Amigos, Jill was very keen to see the Warm Springs Seating and Wheeled Mobility Clinic where we were shown yet another two seating pressure 'mappers', although Carlyle McConnell, the Administrator of Out Patient Services, told us that they rarely use these anymore because the actual cushions being used on the wheelchairs have now become so sophisticated. This facility was also home to the orthotic and prosthetic technicians. They make all their braces on site and polio survivors come from across the USA and Canada to have their old braces repaired because they can't find anyone else to do it. Of course, newer, lighter materials such as carbon fibre could be used for bracing, but people seem to want to stick to what they know works for them.

A definite bonus of this last visit is that Jill was offered the loan of an electric scooter and did she jump at the chance! I can tell you I was certainly relieved as well because I'd had to hold her wheelchair back whilst going down a very steep hill and I wasn't looking forward to pushing her back up. Since then she's been all over the place because EVERYWHERE is accessible and all the doors open automatically as you approach. Because of its age, certain buildings and facilities are definitely in need of a bit of TLC but as a public operation, money for extras such as 'beautification' is, by necessity, a secondary consideration. However, overall, it appears to be both a restful yet dynamic complex – perfect for rehabilitation.

I was starting to get a bit of sensory overload by this stage, not to mention taking up all of Greg's valuable time, so we took a break. I spent the next couple of hours working on the computer and uploading my previous day's report. Jill had hopped into the car to check out a horse riding place, as she was starting to suffer withdrawal symptoms from not being on a horse. Unfortunately, it was closed but she came back just in time to join Greg and me for dinner. On the way to the restaurant, Greg drove by McCarthy Cottage which was built by FDR in 1927 and where he lived when he was in Warm Springs until 1932 when "The Little Whitehouse" was built. McCarthy Cottage was actually used on the set for the "Warm Springs" movie. Greg took us for a look around the inside and it was quite awesome to be walking through the same rooms as one of the most significant polio survivors and adored American Presidents in history. After that, we were taken to one of FDR's favourite picnic spots called "Dowdell's Knob" which he often visited to look over the view and contemplate life, I suppose. He was once reported as saying that anyone who felt down and could not be uplifted by the majesty of the view, was beyond rehabilitation.

After yet another mega-meal topped off by a delicious pecan pie, it was time for bed.

## Atlanta/Warm Springs Thursday 1 May 2008

Today I decided to sleep in and skip the breakfast that is served between 6.00am and 8.00am. After all, with so much food being consumed lately, I felt my body could do with both the physical and dietary rest. I planned to go to “The Little Whitehouse” and the historic pools in the morning and meet up with Mike Shadix to discuss his historical library collection in the afternoon. Jill was desperate for a horse ride and rang the place she had visited the previous day to see if something could be arranged. SUCCESS! They would take her out at 1.00pm. I made my way to visit “The Little Whitehouse” myself while Jill used the computer to do a few more ‘jottings’. Eventually, we’ll be able to upload them onto the website – but I have been hogging the computer. I promised to be back in time for Jill to drive the car to the stables.

Greg had asked his PA, Denise, to see if free admission to “The Little Whitehouse” could be arranged for me (how thoughtful), and I was duly warned there was a battalion of school children visiting. However, I did manage to find space between the waves of guided tours and found an idyllic property to wander through. The museum at the entrance was very interesting, showing (among other things) the original hand controlled car used by FDR, and an astonishing array of walking sticks that were sent to him from all over the USA. I’m not sure they were all practical, but many were real works of art. I then walked along a pathway of flags representing all the states of America flying above a specimen of their state stone, many of them cut into the shape of their respective states. All were distinctly different and some were quite beautiful. Finally, “The Little Whitehouse” came in to view and it really was – “little”, that is. With the trend for huge, impressive buildings these days, it was interesting to see just how modestly a President could live. The last stop was a room containing FDR’s famous “Unfinished Portrait”. Painter, Elizabeth Shoumatoff, had commenced this portrait when FDR suffered a fatal stroke on April 12, 1945. She went on to produce a finished version of the portrait but the “Unfinished Portrait” is the most poignant.

With time marching on and Jill champing at the bit, I moved on to the historic hydrotherapy pools, where FDR first went for rehabilitation. These pools sit on top of the warm springs after which the town gets its name. The flow is up to 914 gallons per minute and the water averages 88 degrees (Fahrenheit) throughout the year. This water also supplies all the needs of “The Little Whitehouse” and the Warm Springs Rehabilitation complex.

According to the Georgia State Parks & Historic Sites brochure, “When FDR found swimming in the warm buoyant waters helped his paralyzed legs, he bought the once prosperous resort area and converted it into a health spa for treating other polio patients. In 1927, the facility was incorporated as the Warm Springs Foundation.” “Once the new indoor pool was built on the Institute grounds in 1942, the outdoor pool was seldom used for therapy and over the years fell into disrepair. In the 1990’s, utilizing both public and private funds the Georgia Department of Natural Resources restored the facility.” This site was also used in the making of the movie “Warm Springs”. Unfortunately, these days, the pools are only filled on special occasions as the spring underneath is severely undermining the integrity of the structure. As well as that, the warm water produces an algae bloom that would require daily cleaning, and the cost of resourcing this type of operation is clearly prohibitive.

Oh, no! Is that the time? Jill was just about to drive her motorized scooter all the way to the stables (some 8 miles away) as I came screeching into the car park. Suffice to say, she was much happier when she returned after a couple of hours on her beloved beast of choice.

I spent the afternoon with Mike as we swapped historical photos and watched a couple of incredible educational videos that he is keen to get digitized before the images are lost to antiquity. I recorded him talking about the history of the Roosevelt Warm Springs Institute for Rehabilitation, which is clearly his passion after 17 years of diligent archiving. He presented me with 3 books, 2 were bound

papers presented at consecutive “Research Symposiums on the Late Effects of Poliomyelitis” held at Warm Springs, and the other was “The Squire of Warm Springs: FDR in Georgia, 1924-1945” by Theo Lippman, Jr. Although I’m keen to read them, I’m going to have to send post them back to Australia to make sure I keep my weight load down (it’s a shame I can’t do much about my body weight though).

Tomorrow we say farewell to Warm Springs and the wonderful hospitality, serenity and inspiration it has provided. We’ll jump into the ole’ convertible and drive back to Atlanta for a quick look around before flying on to Washington first thing Saturday morning. The “Roosevelt Way” has certainly worked for me.

## **Atlanta/Warm Spring Friday 2 May 2008**

Well, there's not a real lot to say about today as we left Warm Springs to drive back to Atlanta for an overnight stay at the airport Hilton before flying off to Washington, DC tomorrow morning. We did have a final farewell with Greg Schmieg and, in response to a variety of questions, showed him an actual map of Australia. It's hard for American's to reconcile the size of Australia compared to the relatively small population we have. However, Greg is now keen to reciprocate the visit and I've already been working on an itinerary for him. Before we left, Greg presented us each is 2 books – one, the story of a well known polio survivor and the other, a book on FDR at Warm Springs – as well as a copy of the "Warm Springs" DVD which I'm pleased to be able to add to my resources. If you haven't seen this movie, let me assure you that it is very inspiring and a good watch. I already have 2 copies, and I'll be happy to loan them out on my return.

The only notable thing on our return was a half hour traffic jam on a 6 lane highway that, when it finally cleared, we could see no reason for. With Jill's expert navigation, we managed to find our way to the Hilton to unload our bags, then back to the rental company where we said goodbye to the convertible. Someone must have been smiling down on us because, just as we thought we would have to climb aboard a shuttle bus to take us back to the airport, then catch another shuttle from the airport to bring us to the Hilton, the staff decided to drive us directly back in one of the rental cars. Jill's wheelchair speaks volumes!

I had contemplated going into Atlanta proper, but decided to spend the afternoon uploading photos to the website and catching up with my nearest and dearest with whom I had been out of contact with due to the lack of cell phone coverage in Warm Springs. Jill also spent the time productively by completing "Jill's Jottings", which I will be uploading with this report.

What awaits us in Washington, DC? Hopefully, we'll be able to do a bit of sightseeing . . .

## Washington DC Saturday 3 May 2008

I'm waiting for a chance to have a nice sleep in! This morning we had to meet down in the lobby at 7.30am to wait for a shuttle that comes around every 15-20 mins to take us to the airport for our 9.20am flight to Washington. No time for breakfast – what I thought were bagels at the Starbucks Coffee stand actually turned out to be doughnuts. Not my type of morning fare. But I did get a cappuccino. Unfortunately, no chocolate sprinkles, only cinnamon or nutmeg (on coffee??). So then I thought I'd get something at the airport. Wrong again! No such thing as good old toast but I could have bought any variety of burgers and fries . . . With that selection on offer, I decided to wait until we reached Washington. By the time we arrived, I thought I may as well wait for lunch. However, it took a little while to get out of the airport and the usual 35-40 minute taxi ride to Washington was extended by about 25 mins as we battled our way through some freeway lane closures and bumper to bumper, stand-still traffic. Maybe this was the start of my new diet. We finally arrived at the Kellogg Conference Hotel at Gallaudet University around 1.30pm and I hastily made my way to the cafeteria for a very welcomed late lunch. The food was buffet style and great value at \$8.08 for 'all you can eat'. Lots of healthy choices and we finally saw TEA on offer. I'm sure we'll be regular patrons over the next 5 days.

One interesting fact I hadn't noted about Gallaudet University when I originally booked the accommodation on line, is that it is for deaf students. The receptionist at the check in wasn't deaf and there were numerous conference participants milling around all merrily chatting away to each other. So we were in for a bit of a surprise when stopped one of the students to ask if we were headed the right way for the cafeteria. She indicated that she was deaf but we managed to communicate what we wanted, she responded, and off we went. When we got to there, another student came in behind us and asked if we wanted her to interpret for us as the cashier was also deaf. I finally started to twig that this was not just the odd occurrence and she explained the nature of the facility. It certainly made for a nice, quiet meal, which is unusual when there are so many young people en masse.

Apparently Gallaudet University is the only university in the world specifically designed to accommodate deaf and hard of hearing students, and was founded in 1864. One of their little "Did You Know?" quotes claims that "The football huddle originated at Gallaudet University when the football team found that opposing teams were reading their signed messages and intercepting the plays."

The Kellogg Conference Hotel has all the mod cons except that it is set in amongst a wide expanse of campus buildings and lovely green lawns and gardens. Plenty of squirrels here as well. I wanted to take a photo of one that was on a tree trunk but it kept running around to the other side. It became like a game as I chased it around and around the tree, and I still didn't get a shot! My room overlooks trees and a baseball pitch directly in front and to the side, an interesting old building with the distinctive Washington Monument obelisk rising above it in the background. Interestingly, there is a door 'bell' for the rooms, which is silent but the alcove light flickers off and on so that a person who can't hear it would be aware that someone was at the door.

While I had a few boring but necessary personal things to attend to, Jill went exploring. Kellogg has a shuttle that takes people to various parts of Washington. We agreed to meet up at 7.00pm for dinner and when I finished what I needed to do, I started putting this report together. At 7.00pm I rang Jill's room – no answer. I then went and knocked on the door – nothing. I went and asked at reception and the shuttle driver told me Jill had called to be picked up but when he got there, she couldn't be found. Jill doesn't carry a mobile phone so she had to find a public phone box to make that call. By 8.00pm I was getting really worried and about to call out the cavalry, when there was a knock at the door. Jill was back from the front, none the worse for wear, but full of the spirit of adventure. I'll let her tell you what happened in "Jill's Jottings."

Tomorrow we'll have a sightseeing day (after a good sleep in). We plan to buy a ticket for a hop on and off tourist bus that takes people around to all the things worth seeing and get off when we feel like it. We are also looking at taking a 50 minute riverboat tour on The Potomac River which should be fun. Washington – here we come!

## Washington DC Sunday 4 May 2008

After a good night's sleep I was even happier to be able to get a good morning's breakfast at the bistro downstairs. The bowl of mixed berries and toasted blueberry bagel with cream cheese were a perfect to start the day. We caught the 10.05am Gallaudet University shuttle to Union Station to meet up with the Washington Sightseeing Bus. There are 26 stops you can get on or off at, although with Jill's wheelchair, we weren't planning too many 'off's'. I obviously attract tour groups of children (read "The Little Whitehouse", Warm Springs) because after a short ride, we were joined by what seemed like hundreds of Spanish speaking pre-pubescent's with a couple of adults to supervise. A few hours later (well, 9 stops actually) the National Cathedral came into view where they all piled off – for religious study, I suppose. Not far from there is Embassy Row, and I wasn't quite quick enough to take a photo of the British Embassy, complete with a large, bronze sculpture of my benefactor for this trip, Sir Winston Churchill.

We decided we'd like to go for a cruise on The Potomac River so disembarked in Georgetown, a lovely Harbour-side suburb with lots of trendy shopping and eating options available. We headed on down a fairly steep hill (I wasn't looking forward to going back up . . .) to the Georgetown Waterfront Park where we joined other happy Sunday holiday-makers basking in the glorious sunshine. A short time later we were aboard the "George Washington" National River Tours boat enjoying the views.

Time to get back up THAT hill! Jill walked a bit, I pushed a bit, we both stopped a lot, but we eventually made it thinking we could now eat that extra piece of triple chocolate fudge cake. We boarded the bus, each with a different agenda in mind – Jill to see the National Air & Space Museum (which she didn't end up getting to) and the American Indian Museum (which she did) – and me to see the sculpture park and later the United States Botanical Garden (USBG). Not that I knew that I was going to the USBG but while I was wandering around the attractive but smaller-than-anticipated sculpture park, one of the omnipresent authorities of some sort stuck up a conversation with me as I was taking photos. He said I was the second Australian he'd spoken to that day and I thought, "He must be an Aussie magnet in the same way I'm a school kid magnet". He then surmised that, being from Australia (Melbourne NOT Sydney), I must be into the great outdoors, or nature at the very least, and pointed me in the direction of the USBG. This was actually a good suggestion and not too far to walk. It also took me close to Capitol Hill which was interesting from a distance, although I didn't feel the need to venture any closer.

After meandering around the lovely USBG for a while, I found my way back to Union Station on foot (another piece of cake) and had a look around the building. It's a massive structure and very impressive inside with huge vaulted ceilings and intricately patterned windows. Jill and I had agreed to meet again at 7.00pm for tea and this time she had my mobile phone number in the event of any mishaps. While I was waiting for the Uni shuttle to pick me up, I started chatting with another woman, who was staying at the Kellogg Conference Hotel, about why we were there, etc. Of course, I mentioned my study tour and she told me her husband had contracted polio as an adult and was experiencing a range of symptoms that his neurologist wasn't able to diagnose. Sound familiar? Unfortunately, she lives in Texas or I would have suggested she contact Dr Lauro Halstead at the National Rehab Hospital (NRH) here in Washington.

Tomorrow we've been invited to lunch with Wendy Wilmer, President of The Polio Society based in Washington, DC ([www.poliosociety.org](http://www.poliosociety.org)), together with some others on the Board of Directors. Dr Halstead, who we are meeting up with at the NRH on Tuesday, is on their advisory panel. It's interesting how meetings and food go hand in hand. I suppose this format has been going on for time immemorial, and I'm certainly enjoying these occasions.

## Washington DC Monday 5 May 2008

We have been really blessed with fine weather on our travels, and today was no exception. It started off a bit more exciting than usual with the fire alarm system going shaking me out of my slumber. I immediately pulled on some jeans, grabbed my bag and heading for Jill's room. I was knocking madly on door but the siren was so loud I couldn't hear anything, and the door wasn't answered, so I assumed Jill had already exited. However, as the other guests and I were milling around in various stages of night attire, groggily trying to figure what direction the stairs were in (we would have been burned to a crisp if there had been a real fire) I figured that Jill would have real problems getting down 4 flights of stairs. Things were soon back to normal – the alarm being triggered off by something to do with the renovations currently taking place – and I went in search of a blackened corpse . . . This time Jill happily opened the door to my knocking and I grumpily made sure she knew where the stairwell was. It's not as though there aren't emergency exit signs everywhere, but who reads them? (Me, from now on!) And when you're not quite with it and in a bit of a panic, it's easy to become disoriented.

After breakfast, I set up the computer for Jill to do her "Jottings" and caught a shuttle to Union Station where I intended to have a really good look around as it is the only place I've been to look at shops so far (apart from airports). I'm not really a 'shopper' but it is interesting to compare merchandise from place to place. I found a gift shop that featured arts and crafts from American artisans and came out quite a bit poorer for having bought 2 pairs of earrings by the same artist and a brooch for my mother. Well, at least they won't add too much weight to my luggage.

By then it was time to meet up with Jill, who was being dropped off by another shuttle, for a taxi ride to the Banana Café and our luncheon meeting with Wendy Wilmer (President) and Elver Ariza (Board Member) from The Polio Society. The Banana Café is renowned for its Cuban, Mexican and Puerto Rican Cuisine, and we all had something interesting while sitting in the sunshine. Wendy was very interested in finding out all about how we work things in Australia and shared some of what was going on for The Polio Society. Their Board of Directors, made up of 9 members, meets on a quarterly basis and operates on a similar basis to our Australian 'Networks' except they do not oversee support groups. According to their Mission statement, The Polio Society aim "To make a difference in the lives of people who have Post-Polio Syndrome and other polio-related problems. We provide education and resources to polio survivors, their families and caregivers along with health care providers, policy makers, and others who affect the well-being of people who had polio."

Wendy contracted polio in 1952 as an infant and after the age of 8, did not wear or use any assistive devices for several years. She works as an actor and has always had a very active lifestyle. Wendy was in her mid-30's when post-polio syndrome (PPS) was first mentioned and she has since taken to wearing a leg brace and using a walking stick, as well as a wheelchair from time to time. She has periods of "hitting the wall" fatigue and, in typical polio-style, knows she does far more than her energy levels can support. Wendy became involved with The Polio Society because she is a keen advocate for disability rights. She became the President in 2007.

We also learned about Elver Ariza who, at only 38 yo, is one of the younger polio survivors on the Board. Elver was born in Colombia and contracted polio in 1969 at the age of 6 months. He was lucky to survive the illness due to the lack of medical resources available to his farming parents. Through sheer determination, they got him diagnosed and stabilized at Columbia's "Roosevelt Institute". He went on to obtain a Master's Degree in Food Engineering from the University of Bogota and found work in his field. However, Colombia proved to be a difficult place to live with a disability. This, together with development of PPS, made Elver seek further opportunities in USA. Without being able to speak a word of English, he moved to the US on a student visa in 2001 and studied computers, international business and economic policy.

He is still on a student visa but continuing to apply for a change in status so he can find permanent, paid employment and qualify for medical insurance. At this stage, Elver has to pay for every service and piece of equipment he needs.

Discussions led to the problems that many ageing polio survivors and related groups are facing and that is about how to keep on keeping on. The Polio Society is challenged by the need to fundraise, find new members and keep 'old' ones, delegating work amongst the members who are all experiencing some form of PPS symptoms, and trying to remain relevant and informative for their members. Of course, there are no easy solutions but success does tend to rely on being able to access a number of dedicated, multi-skilled people to work together. As the old saying goes, "Many hands make light work." Although there seems to be a belief that polio survivors are a "dying breed", there are still many younger people like Elver, and even those who are experiencing symptoms but are unaware that PPS even exists, who will need to access information and resources in years to come. Polio survivors I have worked with claim, "We're not dead yet!" and I hope to play my part in ensuring services are available for as long as needed.

**Washington DC**  
**Tuesday 6 May 2008**

Do I sound Irish to you? Those who know me would vouch for the fact that my accent is pure Australian. However, this is the second time someone has sworn my accent is from Ireland. Whilst waiting for our shuttle, an Italian woman mentioned it saying she should know because she lived in Ireland for a year! Well, maybe she needs to travel over to our side of the globe for a widening of her cultural horizons . . . That's not to say both Jill and I haven't been asked about our accents on numerous occasions. Of course, this was to be expected. There have been some interesting misunderstandings such as when I was asking someone to change dollar 'notes' before I twigged that I should have been using the word 'bills' after the seventh "excuse me?". That type of thing.

Today we were off to the National Rehabilitation Hospital to meet with Lauro S Halstead, MD, who contributed to and edited the 2nd edition of "Managing Post-Polio: A Guide to Living and Aging Well with Post-Polio Syndrome" printed in 2006 – one of many publications produced throughout his career. Dr Halstead contracted polio at the age of 18 and, as he writes in Chapter 15 of his book under "The Lessons and Legacies of Polio", he ". . . made the trip from iron lung to wheelchair and then to no assistive device within six months. This experience taught me a number of things, including denial. I had recovered and, although my right arm remained largely paralyzed, I did not think of myself as disabled – just inconvenienced." Dr Halstead went on to graduate from medical school and specialize in the area of Internal and Neuro/Rehab Medicine, working primarily with people who had spinal cord injury. In the early 1980's, Dr Halstead started experiencing extreme fatigue – something he had never felt before. A little while later, he noticed he couldn't walk as far as he used to and his legs felt 'heavy' and painful. With ready access to a number of specialists, he underwent numerous tests, none of which resulted in any conclusive diagnosis. He then started to research various medical publications and chanced upon one focussing on a sample of polio survivors that seemed describe his symptoms. Quoting from his book again under "The Legacy of Emotional Isolation", Dr Halstead writes, "Speaking for myself, the detachment I learned made it difficult to express emotions and share deeply in relationships. The physical losses sensitized me to other kinds of losses. I contracted polio in 1954 but did not experience being disabled until 1983, almost 30 years later, when I was 46. Not until I joined a support group and began talking with other polios about my new weakness and pain did I begin to grieve for the body I had lost 30 years earlier."

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

Ginger then deposited us back at Dr Halstead's small office which really only had room for 2 people, so while I was videotaping an interview with him, Jill found a computer and updated "Jill's Jottings". We discussed numerous aspects of the workings of NRH's Post-Polio Clinic, including the thorny subject of who will be his successor? Unfortunately, a well regarded colleague who had operated a second 'team' of post-polio health professionals recently left and there is no guarantee that a suitable replacement will be found, i.e. a physician interested in working with and learning from the polio community.

The specifics of NRH's Post-Polio Clinic are interesting insofar as the initial assessment is done over a period of 1½ days. The schedule is as follows:

### **Day 1**

7.50 – 8.00am Registration  
8.00 – 8.45am PT Evaluation  
9.00 – 9.45am OT Evaluation  
10.00 – 10.30am Nurse Evaluation  
10.30 – 11.30am Examination with MD  
11.30 – 2.00pm Lunch  
2.00 – 3.00pm Other consults as needed (eg. Orthotist)  
3.00 – 4.45pm Electromyogram, if needed (EMG/muscle test)

### **Day 2**

10.30 – 11.00am Social Work consult  
11.00 – 11.30am Joint session with PT & OT  
11.30 – 12.00pm Wrap up meeting with all disciplines

The theory is that the overnight period is a good time for people to discuss the day's events with their 'significant others' and to generally come to terms with what has been discussed during the day. They can then ask specific questions during the next day's activities. 'Significant others' are also encouraged to attend the 'Wrap Up' meeting, which is important to enable all the relevant specialists to ensure suggested management strategies have been fully explained and understood, referrals to local community practitioners can be made, and any last questions addressed. This extraordinary service is paid for through private health insurance. If you were to pay for it yourself, it would cost around \$2,000 - \$2,500 USD. Dr Halstead sees approximately 2 new polios for assessment each week and up to 250 – including reviews – per year. As you would expect, the feedback from these sessions is glowing and we can only assume people comply with the suggestions made and actually improve somewhat after such a thorough going-over.

We took our leave from the NRH for the afternoon, before heading back to Dr Halstead's home in the evening for a dinner invitation with his charming wife, Jessica Scheer, a Research Professor at the Department of Prevention and Community Health, and 15 year old son, Alex. It was an excellent occasion to relax on the back decking of their house located in a gorgeous, leafy suburb on the edge of a state park. We had a lovely, balmy night and all seemed to enjoy each other's company and 'cultural exchange'. Jessica learned about "loo's" and Alex was curious about "uni's". I had to spell the word "tyres" and verbally compare it to "ties".

Dr Halstead was invited by the Post-Polio Network (NSW) to speak at a conference in 2001, just when 9/11 laid to rest any imminent travel plans for the family. Hopefully, these plans can be resurrected – perhaps via "Polio Australia" – sometime in the not-too-distant future. It would be an exciting opportunity to hear from such a respected leader in the field of Post-Polio. Jessica Scheer is also well versed in working with polio survivors, with a wealth of information to share on the subject herself. And, just on a personal level, it would be a pleasure to meet up with them again in Australia.

## **Washington DC**

### **Wednesday 7 May 2008**

One last sight I had to see in Washington was the FDR Memorial. Jill and I shuttled over to the somewhat out of the way location and were impressed with the thought put into the display. It also has the only sculpture of Franklin Roosevelt obviously sitting in a wheelchair. This was a late addition, as another, earlier sculpture shows a more common image of him sitting with a cape draped around the chair. Following on from our Warm Springs experience, we felt that visiting this Memorial rounded off our experience of FDR's contribution to the polio cause.

After finding our way back to the main drag of the National Mall, Jill and I parted company to do our own sightseeing. Having pushed Jill from the Memorial for about 1½ miles in some pretty warm midday weather, I was keen find a place to sit and eat. This I did at the American Indian Museum that Jill had been to a couple of days earlier. Although it was clearly a wonderful museum with lots of interesting displays, I really felt a bit washed out and continued walking towards Union Station to pick up the shuttle back to the Hotel. All in all, I had walked about 10 kms and was daydreaming about extra chocolate cake again . . . No doubt, Jill will tell you all about her day in "Jill's Jottings".

So, the airport shuttle service is booked for around 9.00am tomorrow - even though we don't fly until 1.20pm – but being a shuttle, it needs to pick up more people along the way. Then it will be time to say goodbye to Washington. I can honestly say I enjoyed my stay and the people I met. I have even learned a bit of sign language staying in the grounds of the Gallaudet University campus for deaf students.

Tomorrow we're off Johnstown via Pittsburgh in Pennsylvania. Another hire car, another city . . .

**Johnstown, Pennsylvania**  
**Thursday 8 May 2008**

Although we weren't due to fly out until 1.18pm today, the very helpful desk staff at the Kellogg Conference Hotel took me very literally regarding wanted to save money on the trip back to the airport and, instead of booking a taxi for us at 11.00am, we were asked to be ready for a shuttle pick up at 9.00am. Not quite the relaxed morning I had in mind but it was half the price, so it all worked out in the end.

It turned out to be a good day to leave, as the weather has turned drizzly and we would have just been killing time wherever we were. We had plenty of time to wander around the airport and Jill was tempted to buy a brooch of prancing horses. Unfortunately, the plane was too small to warrant a walkway, so Jill had to clamber up (and down again) a dozen or so steps to the main cabin. Very awkward. The whole flight was like being in pea-soup and we didn't break through the cloud until we were just about touching down in Pittsburgh, Pennsylvania. More drizzle. According to the radio reports, this pattern is due to stay around for and 6 days or so.

Although I booked another hire car to drive from Pittsburgh airport to Johnstown, I was pleased to have done the convertible 'thing' in Atlanta/Warm Springs in the sunshine. This time, we just have a basic Nissan Sentra – 4 door / 4 cylinder sedan. Once again, Jill expertly navigated us through heavy Pittsburgh city traffic (although it was only 3.30pm) and out the other side on a series of freeways. We were also snagged by numerous road works which slowed us down so that we didn't arrive at our "Holiday Inn Express" hotel until 6.00pm. However, apart from the weather, roadworks and anxiety about driving on unfamiliar roads, we enjoyed the lovely scenery all around. Lots of treed hills and wide rivers. Very green.

The hotel is standard but clean and comfortable AND free wireless internet connection. Oh, and it's right next door to the John P Murtha Neuroscience and Pain Institute where we have a full day scheduled tomorrow. We had the pleasant surprise of being greeted with a 'gift pack' each, containing a greeting card, information about the Institute, two PPS DVD's (one on Yoga for PP patients), and 3 books which will be a great addition to our library - two I've read and one I haven't, called "Living with Polio: The Epidemic and its Survivors" by Daniel J Wilson. There was also a treat that looks like two cakey biscuits (or cookies) jammed together with a thick layer of peanut butter. So, the neuro and cardiac specialists still have a way to go in providing a team approach to "whole health" messages, I'm thinking . . . Mind you, after a two hour drive, a sugar/fat fix can be very tempting.

The VERY BEST thing our friends at John P Murtha Neuroscience and Pain Institute did was to leave an electric scooter for Jill to get around on. She is happy, happy, happy. We wandered next door to a bar/diner place for dinner which was fine except that they don't seem to have the regulation of no smoking in eateries here. Maybe because it's predominantly a bar, I'm not sure. I just know I came out smelling like an ashtray – Yuk!

So, tomorrow we're looking forward to meeting up with our generous benefactors for a grand tour of the Institute. More soon.

## Johnstown, Pennsylvania Friday 9 May 2008

For a small town (pop approx 22500), we certainly received a huge welcome from our hosts at John P Murtha Neuroscience and Pain Institute in Johnstown, Pennsylvania ([www.conemaugh.org](http://www.conemaugh.org)). We were met at our hotel at 8.30am by Sharon Lehman, a Research Nurse, who thoughtfully brought over an umbrella for the light drizzle that had continued to fall. As the Institute was right next door, we were safely delivered a couple of minutes later to be greeted by a delicious looking plate of freshly baked bagels. Unfortunately, we had just had breakfast but I certainly enjoyed a raisin bagel at mid-morning.

Sharon explained the set up for the day and gave us a copy of our program. We immediately felt we were in safe, efficient hands. First off, we were herded together with members of the clinic staff for a photo opportunity with Greg Dulak from Marketing/ Communications, as well as a representative from one of the local newspapers. This led to informal introductions with many of the people we were later scheduled to have more 'quality time' with, including Dr William DeMayo, the Medical Director of John P Murtha Neuroscience and Pain Institute (JPMNPI) Specialty Clinics. I hope I get to see some of these photos and any subsequent write up because there were some hilarious moments where we were instructed to "look casual" and "just talk to each other", i.e. staged candid – should be interesting . . .

It was certainly a good 'ice-breaker' for our first interview with Dr DeMayo, who I videotaped giving an overview of the Specialty Clinics he manages which including the Post-Polio Program. Other Neuroscience Specialty Programs include:

- Arts for Healing: Giving Patients New Hope for Relief from Chronic Pain and Neurological Conditions
- Osteoporosis Program
- Stress Reduction
- Healthy Living with a Chronic Condition Program
- Blending Traditional Medicine with Complementary Healing Methods to Treat PPS

Chronic conditions seen at JPMNPI include:

- Amyotrophic Lateral Sclerosis (ALS – Lou Gehrig's Disease)
- Aneurysms
- Arterial Venous Malformations
- Back Pain
- Brain Injuries
- Brain Tumors
- Charcot-Marie-Tooth Disorder
- Chiari Malformations
- Diabetic Neuropathy
- Epilepsy and Seizure Disorders
- Fibromyalgia
- Headaches
- Hemorrhages
- Hydrocephalus
- Infections
- Lupus
- Multiple Sclerosis
- Pain Management
- Parkinson's Disease and Movement Disorders
- Post-Polio Syndrome
- Pseudo Tumor Cerebri
- Skull Base Surgery Conditions and Abnormalities
- Spinal Disorders
- Stroke

There are also a number of interesting research projects that have been undertaken and others that are still to be done. Two of particular interest are: Cognitive Function Status in Polio Survivors with and without PPS (not completed), which I know will be of extreme interest to many; and Hatha Yoga and Meditation in Patients with PPS (completed). The Yoga research study enrolled 23 patients who all participated in a 5 day retreat in Johnstown.

According to an article which appeared in “Alternative Therapies”, Mar/Apr 2004, Vol 10, No 2, “These results showed significant improvements in a patient population where a lack of deterioration is often viewed as success. These patients improved and at the end of 12 weeks they were actively involved in self-care.”

So, you may have deduced by now that JPMNPI is not purely ‘clinical’ in its approach to treating patients. When Dr DeMayo was recruited as the Medical Director 6 years earlier, it was largely due to his philosophy on addressing the total mind, body and spirit with achieve wellness. He came across as a very warm and genuine man, so I’m sure his patients would be equally responsive to his approach.

Other members of the team we met as part of our program were: Sharon Lehman, Research Nurse; Kerri Golden, the Occupational Therapist - contracted from Saint Francis University; Lori Murphy, Physical Therapist; Tim Golden, Orthotist; Jan Goodard, Research Nurse; and Lisa Pasierb, PhD, who gave us a demonstration of the Post Polio Registry Kiosk. This Registry is designed to track polio survivors and their health issues and can be done on-line. We were interested to learn that as part of the PPS assessment process, polio patients were also given an “Osteoporosis Evaluation Score Sheet” to determine if follow-up was required in this area.

All members of the team echoed each other in their support of the mind, body, spirit philosophy espoused by Dr DeMayo and believed that their success was reflected in the fact that they see approx 200 polio survivors per year who make their way to Johnstown from all over the US, and other countries such as Canada, UK and Mexico.

We were then treated to a lunch presentation with other staff members and interested parties such as Judy Seese, a Polio Survivor who features in the Yoga for PPS DVD we were presented with in our “gift pack”, and Heather Brice from the Laurel Highlands Health Sciences Library Consortium – and fellow Australian (from Tasmania)! More about Heather later. Our hostess for the lunch presentation was Barbara Duryea, Director of Research and Development, who was also my main contact at JPMNPI and, therefore, responsible for making all this happen. Barb had put together an entertaining and informative PowerPoint presentation starting with “Where in the world are Mary-ann & Jill?”, an idea taken from a morning breakfast program. She proceeded to lead us through the Johnstown and JPMNPI experience before opening up to a general information exchange around the table. As has been the way during our team meetings, it was also an opportunity for the others around the table to learn more about/refresh their knowledge of what’s going on in their own workplace.

After lunch, we met with Jan Goodard who trained in the area of Therapeutic Uses of Essential Oils. She provided precautionary information such as which oils not to use under various conditions as well as recipes for relaxation, fatigue, insomnia, and pain. She also gave both Jill and me a few samples to try and assured us that you don’t actually have to be able to smell the oils for them to work. As I really enjoy essential oils anyway, Jan was preaching to the converted. One of the blends she gave me was for sleep although I must say that by the end of each day, I haven’t been having much trouble in this regard. Jill is keen to try the blend for pain.

By 4.30pm we were totally zonked. So much information to try and absorb. Just as well I have written and taped information to refer back to. Over lunch, I had talked more with ‘Aussie’ Heather who generously invited us to join her at a violin concert that night. I was very pleased to accept but it wasn’t Jill’s thing. It was a very pleasant evening and Heather offered to show me around a bit of Johnstown the following day. Jill was keen to whiz around on her electric scooter to spent time with Jan Goodard looking at bus timetables and making alternative arrangements.

In summary, John P Murtha Neuroscience and Pain Institute has been an absolute treat to visit. I am really impressed by their whole-health philosophy and willingness to look at the range of traditional and complementary options to treat and manage patients with chronic illnesses.

I think we could learn much from the concept of exploring the 'spiritual' side of healing which, of course, will mean different things to different people. I suppose the key message is not to overlook the less obvious strategies for wellbeing.

For more information on Complementary and Alternative Medicines (CAM) - <http://www.lhslc.org> - MEDLINEplus / CAM

## Johnstown, Pennsylvania Saturday 10 May 2008

Right on time, Heather was at the hotel ready to take me on a tour of Johnstown. The first thing I wanted to do was to visit the “Inclined Plane” which, according to their promotional material, was built in 1891 in the aftermath of the 1889 flood. They claim it is the World’s Steepest Vehicular Incline and is listed on the National Register of historic places. The other good thing about it is that there’s a restaurant at the top where we were due to meet Jill for lunch. True to form, Jill had caught an accessible bus into the city so she could zap around on her motorized scooter, and was actually at the top when by the time we got there.

There was a breathtaking view out over the hills and valleys, including the Conemaugh River which had been one of the funnels for the three major floods that Johnstown is renowned for. The first one, in 1889, destroyed Johnstown and killed more than 2,000 people. One in three bodies couldn’t be identified and are buried in a local cemetery in an area signed as the “Unknown Plot”. Two more floods followed in 1936 and 1977 but were far less destructive. Anyone buying a house in the valleys of Johnstown is required to take out flood insurance, although it’s surprising that they can even get it under the circumstances. Houses in these areas can be bought for as little as \$30-\$40,000 USD. Apparently, ‘Johnstownians’ are considered to have high work ethics and resilience as a result of their adverse history. Sound familiar?

The area was largely settled by Eastern Europeans and there are numerous churches for each of their respective religions – mainly orthodox. At the turn of the 20th century, these immigrants made their way to Johnstown to work in the steel industry. There was also coal being mined in the area with 190 million tons of coal being produced between 1890 and 1962. The nearby town of Windber houses the Coal Heritage Center and is also close to the Flight 93 Memorial. This flight was significant in the 9/11 tragedy as the plane destined to be crashed into either the White House or the Capitol building. However, the passengers on the flight managed to gain some kind of control and instead, the hijackers ended up crashing the plane into a field.

We visited the Flood Museum where we viewed a film on the 1889 disaster, and then headed to the Unknown Plot. I had made mention that I hadn’t really seen any shopping centres since we’d been in the USA, so Heather took me to one close by so I could look at all the stuff I didn’t want. Mind you, she ended up buying a bargain-priced top on the last day of a sale, so the trip wasn’t in vain. We then popped in to a supermarket for some pre-prepared food to take back to Jill for dinner and I said my farewell. Heather had been a fabulous tour guide and I learned a lot.

Jill had left us after lunch to meet up with Jan Goodard who had offered to show her around the Heritage Discovery Center. Unfortunately, Jill was a bit anxious about her scooter being low on charge and not having a huge amount of time before getting herself to the bus stop, so they just found a place to chat over coffee and recharge the battery. I’m sure Jill will talk all about it in “Jill’s Jottings”.

On returning to the hotel, our new friends at the John P Murtha Institute had one final ‘gift’ for us and that was a zero room charge. My contact, Barbara Duryea, explained that it was all part of their ‘International Relations and Cultural Exchange’. How fortunate are we?

Some things I was made acutely aware of on my tour were:

- Water everywhere - dripping taps, toilets that flush forever (no dual systems here), and people watering down their driveways and washing cars. It was really hard not cringe at the seeming waste considering our dire circumstances in Melbourne and other parts of Australia.
- The comparative lack of Afro-Americans to other parts of the USA that we have visited.
- No formal fencing around houses. Apparently that sends a message that you don’t like your neighbours. Personally, I believe a little privacy never hurt anyone!

- Lots of American flags in front of houses – supposedly because it was the day before ‘Mother’s Day’. Any excuse for a flag-fly, it seems.
- Speaking of ‘Mother’s Day’, everyone was wishing each other a happy one at every given opportunity. Although we recognise it, being a “Mom” seems to be much bigger business here than in Australia.
- Oh, and don’t refer to your ‘partner’ unless you are in a gay relationship. Mind you, there’s no real substitute unless you use the term ‘significant other’. A bit clumsy, I thought, so why not abbreviate it to ‘SO’. Then you can talk about your ‘SO and SO’. I don’t know, in some instances I guess marriage can simplify things considerably!

Tomorrow we drive back to Pittsburgh for a flight to New York. Start spreading the news . . .

## **Johnstown to New York City Sunday 11 May 2008**

Happy Mother's Day! Of course, I rang my mother last night because while it is currently 9.00pm in New York, it is 11.00am Monday in Melbourne. I know this because I haven't changed the time on my computer. Otherwise life is way too confusing on the other side of the planet.

Although we managed quite a bit of blue sky and sunshine in Johnstown during our sightseeing yesterday afternoon, today was back to chilly drizzle. We took off at about 8.30am for a 12.30pm flight out of Pittsburgh. We only got lost once and had to turn around, but we were still making good time. I didn't actually see any Amish, but whilst we were enjoying our little 'detour', there were lots of sign posts indicating they were around. You really have to get off the main roads to see what's going on in an area, don't you?

Further along the way, I stopped off at a good old 'McDonald's' to use the 'restroom' and bought what I thought was a 'cappuccino'. One mouthful and I decided I would never make THAT mistake again. It was flavoured with something sickly sweet that tended to linger on the tongue. Mmmm. By the time we were approaching Pittsburgh, the weather had really set in and it was raining quite solidly. However, thanks to Jill's expert navigating, we made it to the airport on time.

The flight was only an hour and a half and, before we knew it, we were negotiating the busy airport in Newark. A man sitting next to me on the plane mentioned that we could catch one train from the airport to a station where another train would take us to New York City. We decided on this option as it was only \$15.00 for me and \$11.50 for Jill. It was pretty easy really, except for the horrendous gaps between the train and the station platform. Not to mention the state of some of those platforms. Jill was very concerned about the front wheels of her wheelchair getting caught. Once we were on the train, a guard came around and asked if she wanted a ramp to get off. When she answered in the affirmative, he scolded her for not asking for it when boarding because "that's what we're here for." Of course, there were no instructions at the clearly marked disabled entrance to ask for help, nor were there any 'helpful' guards around to ask at the time. In any case, said guard appeared when required and laid out a ramp. Just as well because not only was the platform/train gap wide, there was also about 6 inches difference in height. Scary stuff.

We eventually found our way out of the station and into a taxi to take us 'uptown' to the Hotel Newton on Broadway, arriving around 4.30pm. According to the map, we are very close to the top end of Central Park and the Hudson River is just a street away. All we have seen so far is lots of buildings and cars and people. However, we have 8 nights in New York so should get a good bit of sightseeing in. The hotel staff took one look at Jill's wheelchair and gave her an upgrade into a nice big suite. Apparently, I have also been upgraded from my cheap internet deal room (\$160.00 per night) to something slightly larger. Mind you, I can't imagine anything smaller than what I have now but it's fine for my needs. If I want space, I'll pop in and see Jill in her luxurious abode. Sometimes it pays to have 'additional needs'.

While I went to work on the computer, Jill explored the immediate neighbourhood and found a couple of supermarkets and a place for us to eat. Nothing fancy, but tasty and cheap. I might even get to have an early night before our appointment with Dr Richard Bruno at 9.00am tomorrow morning. More soon.

**New York**  
**Monday 12 May 2008**

With so many taxis in New York City, you wouldn't believe how difficult it was to flag one down at 8.00am this morning. The compounding problem was that it was really cold and starting to drizzle. The front desk had already told me that a private taxi they had called quoted a flat rate fee of \$70 to take us 12 miles across the Hudson River to New Jersey. Apparently there is an \$8.00 toll charge but that seemed like an obscene amount of money to me. By the time we finally did get a taxi to stop, I was chilled to the bone and when he quoted a \$60 flat rate, I just agreed. Although I had a map, this driver was unfamiliar with the area and proceeded to get lost on a major freeway in peak hour traffic. It was not the best way start to the day but it does make a good story!

As a result, we were late arriving for our appointment with Dr Richard Bruno but thankfully so was he, due to a spectacle malfunction of some sort. Quoting from his bio, "Dr. Richard Bruno is a Clinical Psychophysicologist treating and studying mind/body problems, including chronic pain, fatigue and stress, as well as Post-Polio Sequelae (PPS)." (<http://members.aol.com/harvestctr/pps/bios.html>) Wikipedia explains that "While psychophysiology was a discipline off the mainstream of psychological and medical science prior to roughly the 1960 and 1970s, more recently, psychophysiology has found itself positioned at the intersection of psychological and medical science, and its popularity and importance have expanded commensurately with the realization of the inter-relatedness of mind and body." Many people will be aware of his book, "The Polio Paradox" which works on this principle and has made a big difference in the lives and understanding of many polio survivors.

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

Dr Bruno's main focus is on assisting the patient with 'reprogramming' the habits of a lifetime from overworking/overachieving to regulating their pace to match their energy capacity. He likened the people he sees who present with PPS as "driving a car on an empty tank". We also talked about the need for people to eat a proper diet and ensure they get enough protein to strengthen the muscle – especially in the morning. Dr Bruno cited the case of one patient whose energy levels made a dramatic improvement in a short period of time due to eating a solid, protein rich breakfast in the morning. "It's not rocket science", he said. However, it can't be denied that there is a science involved in working with people to achieve their goals of stopping the incremental deterioration of muscle function and increase energy levels. For more than 20 years, Dr Bruno has developed that science and has been responsible for countless successful outcomes.

Dr Bruno is also big on keeping the immunization message on the national agenda and, in response to one of his initiatives, "Actiononline", the Journal of the United Spinal Association, printed the following information earlier this year:

"The Centers for Disease Control has reported that 92% percent of US toddlers are vaccinated against polio. Ninety-two percent sounds good, until you realize that leaves more than one million US children unvaccinated. Between 2005 and 2006, polio vaccination dropped in 20 states and in 10 large cities. While any reductions in polio vaccination are troubling, the location of the cities and states where vaccination dropped is frightening. The cities are major points of entry into the US—New York, Philadelphia, Houston, and Seattle—where a nearly 4% drop was reported.

It's no surprise that toddlers living in poverty have the lowest polio vaccination rates—below 87% in Boston, Indianapolis, Memphis, Phoenix, Detroit, Houston, and Seattle—rates lower than in Vietnam.

Equally frightening, the states with drops in vaccination are on our borders with Mexico and Canada. Arizona, Texas, and New Mexico reported polio vaccination reductions as did 70% of the states that border Canada. Even Minnesota had a decrease, which is both frightening and incomprehensible, since five Minnesota children caught polio in 2005 after coming in contact with someone who imported the poliovirus across the US border.

Polio's recent importation into America and the drops in vaccination have prompted the International Polio Task Force [headed by Dr Richard Bruno] to create 2008 "The National Immunization for Polio Prevention in Infants and Toddlers"—or "NIPP IT"—Campaign.

"NIPP IT" aims to "nip in the bud" America's next polio epidemic by asking each state's department of health to declare April 19-26 (also National Immunization Week) "NIPP IT Week," to prompt parents, health care professionals, and state health officials to ensure that all American children receive four doses of the injectable, inactivated polio vaccine. The NIPP IT Campaign was launched in partnership with "Every Child by Two" (ECBT.org), the organization co-founded by former First Lady Rosalynn Carter to promote immunization of all children by age two."

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

All in all, it was an interesting discussion, and Dr Bruno and I concluded with the idea of possibly collaborating with Rotary International to distribute promotional material via their members to raise awareness of PPS in the community. We also realize that Rotarians often suffer from 'polio fatigue' due to all the work they have done through the years with the Polio Eradication Program. However, we both believe there are many, many more polio survivors experiencing PPS than those who have known how and where to seek advice, so public awareness campaigns are still required.

We left Dr Bruno to see his patient, who had been waiting patiently while I packed up the video recorder and took a couple of photos. It was raining fairly steadily and Jill and I decided to look for lunch before figuring out how to get back to Manhattan. In the end, convenience won out and I decided we should get a taxi. Now, this was almost as difficult as the morning but only because there were NO taxis on the street. Jill finally went into a travel agency who took pity on our bedraggled selves and rang one for us. Guess how much to get back? \$60.00! Must be a magic number. So, I ended up \$120.00 poorer in the purse, but considerably richer for the experience.

Early to bed tonight (didn't manage it last night) and off in search of some sights tomorrow. You'd think there must be something around this town to look at, eh? Hopefully, the weather will clear up a bit for it  
...

**New York**  
**Tuesday 13 May 2008**

Woke up today to blue skies and mild weather. So THIS was the New York I had come to see. And see it I did! Jill and I started out together as we both wanted to see Central Park. It is only a few blocks away from our hotel and a perfect day to see it. Even the street heading towards Central Park was pleasant and tree lined, although the footpaths had seen better days – the pros and cons of tree lined streets, I guess. And when you're pushing a wheelchair, you have to be mindful of every bump (nearly tipped Jill out a couple of times) and even the slightest incline can be a bit of a challenge. I'm hoping all these little 'workouts' are helping me combat the lunches and dinners I've been enjoying.

When we reached Central Park, we had a vague notion that we should head south but signage was not exactly abundant or helpful. A good old "You are here" on any of the few park maps we came across would have been wonderful. So we just wandered around looking at all the green, lush parkland and soaking in the feel of the place. We must have looked liked we knew something because one couple asked us the way to somewhere or other. This has happened to us a few times since we arrived, making it seem that there are more visitors than locals.

After about half an hour of this, Jill indicated that she wanted to strike out in search of the Museum of Natural History, so off she went. (More about that in "Jill's Jottings", I would imagine.) I continued to meander until I came across a little kiosk in an area called "Sheep's Meadow" where I bought a cup of tea and sat down for a while. I then overheard a conversation regarding directions to the "Boathouse" and, as I had seen it in a couple of movies, I decided to check it out. It looks very pleasant and I'm thinking of suggesting it for our next lunch meeting tomorrow. Apparently, the good weather isn't forecast to last, so we may as well make the best of it. Mind you, a burger costs around \$19.00, but it should all be awfully civilized . . . I decided to start making my way out of the park, past a band of jazz musicians, the ubiquitous groups of school children, and nannies with their charges.

As I reached the exit, a gust of wind caused a flurry of some kind of blossom or floaty seed pod to rain down on the street. It was quite something, but clearly the cause of so many sneezes and nose blowings going on around me. I had passed numerous vendors selling large, warm 'bread' pretzels (as opposed to the snacks you get in packets), so I bought one to see what they were like. Not too bad, as it turns out, but I couldn't finish it all.

Dozens of tourist buses had been passing me by and I finally came to a corner where I could buy a ticket for a tour of 'Downtown'. This tour took us around Greenwich Village, Times Square, Empire State Building, Soho, Chinatown, Little Italy, East Village, Rockefeller Center, the World Trade Centre, Wall Street, the Theatre District, Madison Square Garden, Carnegie Hall, and past the Ground Zero site. In Greenwich Village there is a chain mail fence mounted with hundreds, maybe even thousands, of small tiles that have been made by school children all over the USA as a memorial to the 9-11 tragedy.

The only stop I got off at was "Macy's" to see what all the fuss was about. Well it's big, and it's a store, and it's got lots and lots of stuff to buy. Within a short space of time, I was overwhelmed by it all and decided to have lunch (earlier pretzel notwithstanding). They sold an interesting selection of salads by the ½ pound, so quite reasonable. Apparently, you used to be able to get a free canvass 'tote' bag if you went to Macy's Visitor's Centre on Floor 1 ½ (strange but true) but this is no longer the case – I tried. So I just made a bee-line for the exit and hopped back onto the next bus.

I left the bus somewhere 'Midtown' not far from Broadway and walked for about 50 minutes back to the hotel – which is also on Broadway but 'Uptown'. Checked on Jill, who had her own adventures to report, and bought something for dinner from the Thai restaurant next door. A good night to catch up on sleep. Tomorrow we'll be meeting with Susan Fish, a Physical Therapist who has had quite a bit to do with polio survivors.

**New York**  
**Wednesday 14 May 2008**

Today started off bright and sunny but by the afternoon you could tell there was a change coming. It was with that in mind that I asked Susan Fish, the Physical Therapist we were meeting today, if she would be interested in having lunch at the Boathouse in Central Park. Although she had already booked for us at a seafood restaurant (for those who don't know me, I don't eat anything aquatic), she graciously agreed to cancel her booking and off we went to enjoy Central Park in the glorious sunshine.

We caught a taxi this time or we may have lost our way again. We hadn't booked, of course, but managed to get seated within about 10 minutes of arriving in the delightful pavillion section overlooking the lake. Yesterday I had decided that dining at the Boathouse was definitely something I wanted to do before I "kicked the bucket", so I can now concentrate on the other 1,672,000,000 – meaning I have to live a lot longer yet!

Susan was recommended as an interesting person for me to see via Dr Margaret E Backman (Peggy), author of "The Post-Polio Experience: Psychological Insights and Coping Strategies for Polio Survivors and Their Families" – who we are meeting tomorrow. Susan told me that she and Peggy had met through joint presentations a number of years ago, which lead to subsequent referrals to see polio survivors. Susan advised that there are actually no clinics working with post polio in the whole of New York, which is a pretty large area. Of course, there is Dr Bruno across the Hudson River in Englewood, New Jersey, but this lack of service provision for the huge numbers of polio survivors out there, is surprising and unfortunate. Over the years, Susan and Peggy have tried to generate interest in starting such a service but as it is seen as something without much of a future, no-one was prepared to invest in the idea.

Susan is a private Physical Therapist and has learned most of what she does through the polio survivors themselves. Until last year, all her patients were required by law to be referred through a medical practitioner. Although people can now self refer, this doesn't really happen because of the out-of-pocket cost of something like \$120 per session. Although Susan only works to a couple of polio survivors at any given time, she has done so over many years and is probably considered the 'expert' in New York. She, however, is not as confident in her expertise as she would like to be and was keen to learn about our experiences with other physical therapists on our journey.

I think we managed to convince her that no-one was really doing much that was different to how she practiced. The outstanding exception would probably be the Post Polio Clinic at Rancho Los Amigos in Los Angeles, where they had access to equipment and experts that can test the capacity of individual muscle groups and devise an exercise program that specifically works muscles that can be worked, and rests those that are at risk of being overworked. This balance can be difficult to achieve, and Susan has seen the effects of both overworking AND under working post polio muscles - which can be just as harmful. This is where it is so important to have the skills of an informed Physical Therapist.

PT's need to understand the limitations caused by polio's motor neuronal damage, therefore not trying to build muscle strength where this is simply not possible while, at the same time, maintaining strength in areas that can and should be exercised. No exercise at all results in pain and fatigue caused by under worked muscles, not to mention weight gain – which just adds to mobility (and other) problems. Susan was also very interested in the other exceptional work we have seen in this area, i.e. the yoga research study and subsequent DVD produced by John P Murtha's Neurological and Pain Institute in Johnstown.

I think the take home message from today – and every day so far - is that there are individuals and institutes out there doing innovative yet practical things that, in this day and age, can be readily shared through email contact with each other. No practitioners need to work in a vacuum when there are so many ‘experts’ willing to share their knowledge and skills for the benefit of all polio ‘patients’. Sadly for NY polio survivors, Susan is now only working part-time, with a view to retiring in the not too distant future, which will leave a great big hole.

Eventually, after a very pleasant lunch, Jill and I left Susan in Central Park with much bonhomie, and references to meeting up “down under” some day. At Susan’s suggestion, we then made our way to the north end of the park where there is a well noted ‘Conservatory Garden’ in full Spring bloom. We also had a tough negotiation through an area up the top end of Central Park called the “Woodlands”. Apparently, it’s not the safest part of the park, but we didn’t know that at the time and it looked exactly like what it was called, woodland. What that translated to was no easy paths for Jill’s wheelchair and lots of up hills and down dales which I was unable to push Jill up so she had to slowly make her way up on foot.

But we made it back to the hotel at long last and I gave a little wave to the shoe shine man who had given me a lesson in the entrepreneurial nature of “Manhattan’s” the day before. As I was walking past in my trainers, he realized he wouldn’t get a ‘shine’ job but offered to tell me “Where I got my shoes including the street, city, and country”, for a mere \$5.00. Suspecting a ruse, but never being too sure about who knows what, I negotiated down to \$3.00. After asking me if I was a woman of my word, we struck a deal by knocking fists together. So, “Where you got your shoes? On your feet!”, and the rest goes without saying . . . He told me that if he was some kind of psychic, he wouldn’t be sitting around on a corner, shining shoes, now, would he? I thought it was \$3.00 well spent in learning that lesson!

Later that evening, I caught a bus downtown to the theatre district to see “Wicked” at the Gershwin Theatre. Jill had chosen not to attend. Peggy (Dr Margaret Backman, who we are meeting with tomorrow) kindly bought me a ticket some time ago as I couldn’t do it on line without a local delivery address that was connected to my credit card. It was a fabulous musical with great costumes, sets, etc. but only one female ‘restroom’ consisting of 6 toilets for the stalls/orchestra level. What is it with providing decent facilities in a theatre that seats 1933 patrons – approx 50% (or more) of them women? I was a bit concerned on leaving the theatre at 11.00pm and having to walk about 2 kms to get to the part of Broadway that has two way traffic to catch a bus back ‘uptown’, but there were plenty of people around and I only had a couple of minutes to wait until the bus came, so arrived ‘home’ safe and sound. So, “To sleep, perchance to dream . . .”.

**New York**  
**Thursday 15 May 2008**

Dr Margaret E Backman (Peggy), author of “The Post-Polio Experience: Psychological Insights and Coping Strategies for Polio Survivors and Their Families” was our lunch date for today. It’s a very civilised way of conducting a meeting, I must say. Peggy and I had been emailing each other for some time, as she assisted me in sorting out various aspects of my trip to NY. She was determined to give us a gastronomical experience and had proposed a number of eateries before we settled on a ‘Soul Food’ experience in Harlem. This was similar to the ‘Southern Cookin’ experience we’d had in Warm Spring, Georgia, but fry-avoidable. I had beef rib with 2 ‘sides’ consisting of collard greens and candied yams. I realized it was the second or third time I’d had collard greens and I don’t mind them at all. However, the candied yams dish was a one-time experience I don’t think I’ll repeat. Of course, what Soul Food experience would be complete without corn bread?

After yesterday’s meeting with Susan Fish, I realized taping the discussion in a restaurant wasn’t going to work, so Peggy offered to come back to our hotel after lunch.

As indicated in one of her bio’s: “Margaret Backman, PhD, is a Clinical Psychologist [specializing in Health Psychology] in private practice in New York City, who has been working with survivors of polio for many years, providing supportive psychotherapy, lecturing and writing articles on Post Polio Syndrome. Dr. Backman’s most recent book, "The Post-Polio Experience" provides psychological insights and coping strategies for polio survivors and their families.” To purchase online, go to: [www.amazon.com/Post-Polio-Experience-Psychological-Strategies-Survivors/dp/0595386393](http://www.amazon.com/Post-Polio-Experience-Psychological-Strategies-Survivors/dp/0595386393)

Peggy was saying her involvement with post-polio really started in the early to mid 80’s. She had a female client who came to see her with an absolute all kinds of information she had been able to find on post-polio, which was surprising given the limited knowledge of the day. Peggy had already been working with people who had various other illnesses such as kidney problems, cancer, etc. and had written a book: “Psychology of the Physically Ill Patient” directed at clinicians who were working with people with medical problems. Her reason for writing “The Post-Polio Experience” was almost as an ongoing legacy for when she stops practicing. Peggy felt that she had so much knowledge stored up through what she had learned from her patients, that it was important not to lose it, especially for those polio survivors who are yet to experience post-polio.

In one of the chapters of her book, Peggy explains why she doesn’t subscribe to the theory of polio survivors having a particular personality ‘type’. She believes the sample may be biased due to the fact that it is mainly the more assertive and/or confident polio survivor who has been seeking information and assistance for their PPS. As these people are presenting with the issues, these are the ‘personalities’ that have been noted.

Many people who contact both Peggy and Susan Fish (because they are listed in Post-Polio Health International’s Directory for New York), are actually looking for a medical doctor. Finding one who understands about post polio appears to be as much of a problem in a large city like New York and, for that matter, throughout all parts of the USA we’ve visited, as it is in Australia. The message keeps coming through that if your doctor doesn’t seem to want to listen or find out more about post polio, keep looking until you find one who does. That’s all well and good in large areas, but not so easy in the smaller country towns.

Peggy suggested providing the doctor with a small brochure – such as the one developed by the Polio Network Victoria – so they don’t feel swamped with information but can use it to research further. She also believes it’s a good idea to have a list of questions to ask so the patient can feel more focussed during the appointment, thereby not wasting either their or the doctor’s time.

On the subject of a polio survivor being referred by their doctor for psychotherapy, Peggy felt that it was important that the patient understand the 'team work' nature of this type of referral as opposed to them thinking that the doctor had "given up on them" or that it was "all in their head". We went on to talk about the role of the family and 'significant others' in supporting the polio survivor to cope with progressive changes in lifestyle – as well as how dealing with post polio impacts on the lives of people around them. Qualitative changes Peggy has noted in her consultations with polio survivors tend to be more and more about the ageing process and the range of fears this raises for people.

In her practice, Peggy states that the sessions aren't all about the polio but that people have whole lives which may include problems not connected to the polio at all. Then, if you subscribe to stress factors impacting on inflammation thereby exacerbating PPS symptoms, as per the theory presented by Dr Marcia Falconer and Prof Edward Bollenbach, any 'stressors' should really be addressed in order to relieve these symptoms. (More on this theory after visiting with Marcia on 25 May.)

In all these cases, it is helpful to discuss the issues with a psychologist who understands. ParaQuad Victoria actually provides free counselling sessions for polio survivors but it's interesting how few take it up.

However, tomorrow I am going to treat myself to a bit of 'de-stressing' with a couple of hours at a day spa while Jill goes gallivanting 'Downtown' on a sightseeing bus (been there, done that . . .)

**New York**  
**Friday 16 May 2008**

When they forecast rain here, they mean it. It has been raining non-stop today and there are a lot of soggy people on the street. Mind you, there are multiple varieties of colourful rubber boots you can buy in the stores, so they're obviously used to 'weather' here. The bad news is that it's due to continue for the next couple of days so I'm not sure how much more 'quality' sightseeing we'll get to see. Pity some of this rain can't be sent over to Australia. Of course, everyone is talking about how unusual it is because May is usually the best spring weather, yada, yada, yada (that's New York talk for blah, blah, blah).

Haven't caught up with Jill yet, as she was going to pick up a sightseeing bus today. I'm sure she will have made the best of her predicament. Me, I spent most of my day being 'pampered' at a nearby Day Spa and feel quite relaxed. I'll probably go to see a movie tonight to cap off a not very eventful, but very restful day.

**New York**  
**Saturday 17 May 2008**

After all the rain yesterday, today turned out to be bright and sunny – if not overly warm. But good enough for Jill and I to hop on one of the metro buses to take us ‘downtown’ to pick up the New York tourist bus that Jill had bought an “all loops/48 hour” tour ticket for the day before. The metro buses are pretty good insofar as they either lower the bus for a ramp extension, or have a hydraulic lift that just takes the chair up to the floor level of the bus. With the bus systems so busy, it’s a valiant effort on behalf of the driver to assist with this process – however, I was pleasantly surprised to find that people are all quite accommodating about waiting and squashing up to make room.

We thought we should start heading toward Staten Island Ferry. The tour bus took us close and we found our way into the Ferry Terminal only to wait with an already huge and growing crowd for around 30 mins. As it turned out, there was plenty of room for everyone as long as you didn’t mind sitting inside rather than up the top and outside where all the action was taking place, such as when we passed the Statue of Liberty. One annoyance was the need for everyone to disembark on the other side before lining up all over again to catch the next one back!

We then picked up the ‘downtown tour’ bus to complete the circuit to Times Square, which both of us had now done twice. However, it was interesting to hear how different tour guides talked about different points of interest on the tour. Off again at Times Square to catch the ‘uptown tour’. We were beginning to think that we probably wouldn’t make the ‘night tour’. There’s really only so much bus touring you can take in a day. The ‘uptown tour’ took us right past our hotel up along the Hudson River area, into Harlem and Spanish Harlem, where we saw the ‘Cotton Club’ and ‘Apollo Theater’, before heading back down the length of 5th Avenue with all the museums and some pretty expensive real estate – home to some pretty rich people. Names were dropped but, not being much of a ‘groupie’, nothing much has stuck. Except for when we drove past John Lennon’s apartment around Central Park West – also the place where he was shot and killed. Apparently, Yoko Ono still lives there.

By the time we finally got off the bus, it was 6.00pm and I was just about catatonic. We still had to walk a couple of blocks to catch the metro bus back to the hotel, but I was really exhausted from doing practically nothing all day. Jill said she felt OK and was used to not moving a lot – which I suppose was my problem as I’m used to be more physically active and found it tiring just sitting around all day. I almost tipped Jill out of her chair on broken pavements and uneven ‘curb cuts’ a couple of times but I think she’s figuring out how to quickly rebalance now.

We decided to have dinner at a restaurant to cap of the day. Generally, we’ve been in the habit of picking up pre-prepared food from a supermarket and eating in Jill’s more spacious room. At least that way you can avoid paying all those pesky (and progressively expensive) tips. We had Italian, mainly because it was the first one we came to that looked half decent and I was too pooped to push Jill’s chair anymore. Mind you, you can get any kind of food you could think of in New York. Just a couple of doors down, there’s a restaurant promoting itself as “Chinese/Spanish”??? I don’t think so . . .

Only a couple more days to go in New York but I think I’m ready to move on when the time comes. Tomorrow Jill will visit a new horse exhibit at the American Museum of Natural History and Peggy Backman has offered to show me her favourite, the Metropolitan Museum of Art, which is also close to the Guggenheim. I think that should just about do it for the time being.

**New York**  
**Sunday 18 May 2008**

OK, I can finally say I've seen a museum on this trip (the flood museum in Johnstown notwithstanding). As arranged, Peggy Backman met me at the Guggenheim where I gazed up at the inside of this amazingly spiraled building but decided not to wait in the very long cue to spend an exorbitant amount of money to go any further. On one of the bus tours I was on, the guide had said that because the famous architect, Frank Lloyd Wright, didn't like New York he proceeded to design a round building because it's difficult to hang art on round walls . . . Don't know if it's true but it's an interesting 'tour guide' thing to say.

The Metropolitan Museum of Art was a short stroll down the road and, surprisingly, there was no cue to speak of. It's a magnificent example of what a museum can be, with room after room of amazing things to see. There was an ancient Egyptian section displaying partial ruins of the "Temple of Dendur", set within a kind of a moat. Very dramatic. As the name would suggest, it wasn't a general 'history' museum, but dedicated to art from all over the world: painting, sculpture, decorative arts, musical instruments, furniture, photography, drawings, prints, ceramics, bronzes, screens, textiles, glass, metalwork, miniatures, costumes, native carvings, ancient weapons – historical, modern, and contemporary. Peggy told me that 'modern' art includes people like Picasso, Warhol, etc. who are deceased. 'Contemporary' indicates the artist is living.

This is not the sort of museum you can see in one visit. To do it any justice at all, you would need to visit it on several occasions, taking in one wing per floor at a time. We pretty much whizzed through from room to room, picking one or two exhibits that Peggy thought would be of interest – and were – for me. It's very easy to get lost in such a huge space, but Peggy said she has come across many an interesting and, hitherto unknown, exhibit by doing just that. One of the current exhibits is "Superheroes: Fashion and Fantasy" which was fun. They had the actual costumes worn by Toby Maguire in Spiderman, Lynda Carter's Wonder Woman, Cat Woman, Mystique from X-Men, the Iron Man armour worn recently by Robert Downey Jr, and many more fantasy costumes. As I'm a bit of a sci-fi fan, this was something I enjoyed.

However, all that wandering around worked up an appetite and we waited in another cue to be seated for a late lunch in the lovely Petrie Court Café and Wine Bar overlooking part of Central Park. What we saw was rain – and lots of it! It must have bucketed down for a good 2 hours and I wasn't looking forward to leaving the museum to get wet. So, when Peggy left, I spent time in the gift shop. Not surprisingly, lots of umbrellas were being sold . . . I ended up with a new mouse pad (curiously shaped like a hippopotamus) to replace the one I had bought in 2000 at Gaudi's Guelle Park in Barcelona. The last of the big spenders, that's me!

By the time I left the museum, the rain had stopped and I decided to walk back the way I had come. It was a number of blocks but, after yesterday, I really felt I could do with the exercise. I was in for more than I had bargained for when, out of a city of 8,000,000 people, who should I run into at that very time in that very place, but Jill! She was looking a bit tired by then, so I thought she might like to be 'pushed around' a bit more. We made it back in time to pack up for tomorrow's departure for Framingham, Massachusetts. Eight days in New York has been good to meet the three people I had arranged to meet with, and to enjoy a bit of 'down time'. I've even decided it's not as unfriendly or threatening as I remember from a brief 2 day stopover in 1989. But it's busy and heavily populated and can be an absolute assault on the senses, so a slightly slower pace would be a welcome change.

## **New York to Framingham, Massachusetts Monday 19 May 2008**

Still waiting for a bit more of that nice Spring weather everyone says we 'should' be having over on this side of the country. I've got this much to say– it's certainly Green! Flying in to Boston was very pleasant with lots of trees and water everywhere. The airport was in stark contrast to the hustle and bustle of New York. There were even rocking chairs in part of the waiting lounge! And people were actually sitting in them!! No rush, rush, rush – everything was very ordered and everyone was very civilised.

Framingham (pronounced 'frame-ing-ham') is 19 miles West of Boston, which we only glimpsed briefly as we passed by on a very convenient bus that runs express from the airport for \$12.00. We were told by the taxi driver who took us to our Best Western accommodation from the bus depot that Framingham is really a city in itself with a population of 66,910. I can't comment on the township/city of Framingham at this stage, as we have only ventured over the road to see what 'Wal-Mart' is all about (looks just like a great big Target to me) and to the pizza restaurant next door for dinner.

However, speaking of Wal-Mart, Jill and I both ended up spending money on cheap clothes. I actually bought my second pair of jeans here that fit me like a glove and only cost around \$17.00 USD. I also bought 3 plain, V-neck T-shirts for less than \$6.00 each. I had been looking for YEARS to get jeans that fit me in Australia but they're all made in China and the manufactures use some weird body shape to base all their measurements on. In the USA, cheap Wal-Mart stuff appears to be made in Mexico and Nicaragua and probably several other South American countries, but they seem to be perfect for the fuller, mature figure. Of course, there are many full-figured people in the USA, so I suppose they just cater for the market . . .

We are really on the outskirts of Framingham here, not far from Spaulding's International Rehabilitation Center for Polio (IRCP), but just far enough to wonder how we're going to get there tomorrow . . . Oddly, the bus route seems to be a bit 'complicated', and it's not really far enough to catch a taxi, but a bit too far to push Jill in her wheelchair up a hill on a busy, main road with disappearing footpaths, wheeling my briefcase full of recording gear. Tune in tomorrow to see how it all worked out – I know I will!

## **Spaulding Rehabilitation Hospital Network, Framingham Tuesday 20 May 2008**

Well, the universe provided for us again today with the offer of a pick up from our motel to Spaulding by Anna Rubin and Liz McKenney, previous and current Co-ordinators of the International Rehabilitation Center for Polio (IRCP) at Spaulding:

<http://spauldingrehab.org/ourlocations/framingham/ircp>

When I started organizing my Churchill Fellowship Study Tour, my contact was with Anna. At that time, the Medical Director had been Julie K Silver, author of "Post-Polio Syndrome: A guide for polio survivors & their families" published in 2001, and co-author of "Polio Voices: An oral history from the American polio epidemics and worldwide eradication efforts" published in 2007. I was keen to meet with Dr Silver - however, she decided on a total change in career direction last year and is no longer working in the area of post-polio. The current Medical Director is Darren C Rosenberg who has been working with polio survivors since 1999, and with whom we will be meeting up with tomorrow.

Today was quite a full schedule starting with Anna and Liz giving a joint overview of the role of Co-ordinator for the IRCP, although Anna has since moved to an unrelated position within Spaulding. The IRCP sees approx 300 polio survivors per year, many from other states, and some from overseas. There is one large and two smaller polio support groups in Massachusetts - which is three more than in New York - but these are not connected to the clinic apart from accessing services. There is an educational component to the role insofar as giving talks at Rotary and other community meetings to which they are invited. Spaulding also has a school program that focuses on general disability awareness but this also incorporates a polio survivor talking about their own experience. However, the main thrust of the role is to respond to enquiries from polio survivors about the services being offered, and co-ordinate the clinical visits working through potential needs such as: energy conservation and sleep hygiene; exercise; equipment; bracing, orthotics and mobility devices; psychological services; medication and tests.

A key interest I had in talking to Anna was regarding her involvement with the "Oral History Project" which was the basis from Julie Silver's aforementioned book co-authored with Daniel Wilson, PhD. This was a four year project that entailed recruiting polio survivors from all over the USA to work through an interview questionnaire designed by Dr Silver in order to document their account of having had polio. Anna interviewed 200 people which yielded 100 accounts being used in the book. The project was also an instigator for the Smithsonian Institute's Polio Exhibition which we saw in Warm Springs, as well as a 300 strong reunion celebrating 50 years since the release of the Salk vaccine. Anna presented us with a copy of each of Julie Silver's books to add to the Polio Network library.

We were then introduced to Robert (Bob) Drillio who does all the bracing for IRCP patients through his company, "I AM Orthotics and Prosthetics". Bob is clearly very passionate about working with polio survivors and has been doing just that since he was 17 years old. We were shown brace after brace incorporating many innovative features he had designed to make them lighter and more supportive of the polio leg, knee, ankle and foot. There were lots of great designs, including carbon fiber models, but Jill was particularly taken with one design using a new type of knee lock (which she decided would be good for riding horses). For someone only requiring a bit of additional support we both liked a lightweight ankle-foot orthosis used for drop foot called "Foot-up": <http://www.ossur.com/bracesandsupports/ankle/anklefootorthoses/foot-up> Bob quoted a 93.3% success rate in his bracing manufacture and the two patients we met whilst he was seeing them in the afternoon vouched for his superior skills in the area of polio bracing.

Next was a meeting with Psychologist, Dr Stephanie Machell. Stephanie is actually the daughter of a polio survivor, a fact she says puts a lot of patients at ease.

Her inside knowledge gives her a leading edge in understanding and working with the issues surrounding polio and post-polio. At the Ninth International Conference on Post-Polio Health and Ventilator-Assisted Living: Strategies for Living Well, Stephanie gave a presentation entitled: “Trauma Treatment: What is it and What are the Benefits?” which was given an excellent review by attendee, Mary Kinane, and written up on Page 6 of The Lincolnshire Post-Polio Information Newsletter Volume 5 - Issue 5 — August 2005:

<http://www.lincolnshirepostpolio.org.uk/downloads/lincpin/lincpinv5i05august2005web.pdf>.

Stephanie confirmed that counselling helps relieve a variety of ‘stressors’ that, in turn, can help alleviate PPS symptoms such as chronic fatigue. Once again, a professional who is passionate about working with polio survivors and has a wealth of knowledge to share.

Our final appointment for the day was with Carolyn Balinskas, a Speech Therapist working with swallowing disorders, as well as sleep apnea, and cognitive fatigue – which tend to go hand in hand. We found the idea of working with cognitive fatigue interesting for a Speech Therapist but this is not uncommon, apparently. Carolyn teaches patients compensatory strategies for cognitive fatigue such as: limiting periods of concentration; taking frequent breaks; note taking; list making; visualization; “chunking”; mnemonics; prioritizing activities for ‘good days’; and many other techniques. There is a lot of cross over with Occupational Therapists, but it is complementary. I’m sure a number of people would greatly benefit from these types of management strategies.

Carolyn was then kind enough to drive us back to the Best Western, and Liz has offered to collect us again tomorrow morning for a morning with the PT & OT staff, then lunch with a local polio survivor. We are certainly getting good value from this visit!

## **Spaulding Rehabilitation Hospital Network, Framingham Wednesday 21 May 2008**

Liz kindly collected us this morning for our 9:00am meeting with Dr Darren Rosenberg, Medical Director at Spaulding Framingham. His specialty is Physical Medicine and Rehabilitation, also incorporating Osteopathic Manipulative Medicine. Dr Rosenberg took over as Medical Director from Dr Julie Silver last year and is committed to carrying on the International Rehabilitation Center for Polio (IRCP) that she started in 2001, believing that there will still be a need to provide services for post-polio patients through to his retirement. Whereas Dr Silver learned much about treating patients with PPS through Dr Lauro Halstead (see Washington NRH), Dr Rosenberg has honed a full range of skills and treatment options from the established team of therapists and the patients themselves. An interesting emphasis for all staff working with PPS patients is prescribed reading from a variety of books that provide a framework for the experience of a polio survivor and, of course, Dr Silver's book is one of them.

He is currently seeking opportunities to do research in areas such as: sleep apnea in polio survivors; and the effect of osteoporosis in the polio affected limb – especially in training technicians to do bone density scans on the polio affected side, not just the area indicated by standard protocol. Because of his specialty knowledge, Dr Rosenberg believes manipulation has assisted his post polio patients with freeing up motion and ambulation, helping with breathing problems, providing pain relief, and increasing tolerance for bracing. He also believes that there is scope to incorporate people with other neurological conditions into the polio program such as Parkinsons Disease, MS, etc., which may be the future direction for the IRCP.

Dr Rosenberg is justifiably proud of the range of specialists he has working in the Center, and we were later treated to an in depth team case study / information session with PT's, Kristeen Blossfeld and Beth Grill, and OT's, Maria Cole and Laura Ryan, as well as Assistant Site Manager and PT, Terry Sutherland, and Liz McKenney, IRCP Co-ordinator. The case study was an excellent way to present the range of treatment options offered to a post-polio patient who attends the IRCP.

A key to the examination and resulting suggestions for management strategies is based on what goals the patient wants to achieve. In this case study, the patient wanted to gain an understanding of what to expect in the future with PPS and learn ways to reduce fatigue and pain. Of course, a thorough background is taken including medication used; home environment/support system; sleep/fatigue issues; trip/fall history; pain; posture; muscle strength; range of motion; leg length; and functional mobility. After working with the range of therapists available at IRCP, the expected outcomes for this patient included: decrease falls to zero; reduce pain in feet for walking greater than 1 hour; incorporating energy conservation techniques into daily activities; exercise appropriately using PPS exercise parameters; reducing progression of weakness, and improving quality of life. Just as an aside, we were interested in the importance placed on the need for safe footwear in the snow, and the much more severe emphasis on cold sensitivity. At least this is not such a significant issue to contend with in Australia.

A range of tools are used to gain knowledge of the patients' issues, both for the therapist and the patient themselves. One that is not unique, but definitely revealing, is the 'Daily Activity Log' that is used by the OT. This is a simple sheet with 3 columns: Time (6.00am – 12.00am) / Activity / How did you feel? Filled out in hourly increments throughout the day, it gives a clear indication of where their 'hot spots' are and how this can impact on that all important 'energy bank'.

Following an initial assessment, all the therapists involved meet together with the patient and any 'significant other' to discuss the process and to go over any points that need clarification. This is especially important when the patient has come from out of state or overseas as they will need to take information back to their own physicians.

It was made quite clear by all the therapists we spoke to at the IRCP that their sole objective was to assist the patient to achieve their own goals, backed up by the philosophical belief that although they may be 'experts' in their field, the patient is the 'expert' on their own body. This level of respect is a great adjunct to the patient's therapeutic experience.

One of the most promising things about the IRCP is that the team is young, motivated, stable, and committed to ensuring their post polio patients have access skilled clinical services into the future.

To finish off our visit, we were introduced to Lynn Fraser, a local polio survivor and a speaker with the "In My Shoes" 2 day school disability awareness program run by Spaulding Framingham. Lynn and Maria Cole (OT) joined Jill and me for lunch and a good old fashioned chin wag. This was a lovely way to finish of a very successful and well organised visit.

Tomorrow we leave the USA and fly to Toronto in Canada to meet up with Sheila Casemore from Polio Canada. More soon.

## **Polio Canada / Ontario March of Dimes, Ottawa, Canada Thursday 22 and Friday 23 May 2008**

There's not a lot to report on leaving Framingham for Toronto. All went smoothly. The Canadians are a bit more relaxed than the Americans about Customs. Mind you, I do have to go through Chicago and LA before I leave the USA for the last leg to Melbourne next Saturday, so that's something to look forward to. The only thing I found notable was how close Boston airport is to the city. As I was waiting to catch the plane, I could look over at the buildings and wish I'd had the opportunity to see Boston, which is purported to be a lovely city. So many places, so little time . . .

On landing in Toronto, I had the bright idea of a catching train to our hotel via subway, as there was a station just over the road. However, we had to catch a bus to the train station, and by the time I had lugged both our baggage that far, I was well and truly 'over it', so found a taxi and paid \$40 instead of the minimal amount I had in mind. But we got there and I didn't need a chiropractor.

Salubrious, the 'Clarion Hotel' was not – nor was it accessible, with 10 steps leading up to the front door, then another 5 steps up to where you could catch the elevator! Having booked on line, I assumed that an elevator equated to accessible. When am I going to learn – NEVER assume. In any case, Jill managed to drag herself up that obstacle course while I cursed the luggage with every single step. The elevator was an interesting, old fashioned contraption (as was the building) with a door that opened outwards into a narrow corridor and an inner metal cage barrier that was only marginally wider than Jill's wheelchair, which very effective at closing – especially when you were only partially through. But it WAS cheap(ish) and pretty well situated for our needs. We also discovered that the subway station opposite was not accessible, being on the old system (there's a newer system that is totally accessible), so we wouldn't have been able to exit if we had gone all the way through from the airport. With all that excitement, we walked around the corner to the nearest pub and participated in a bit of pain relief.

The next day, after contemplating the vaguaries of accessible public transport in Toronto, we caught a taxi to the "Ontario March of Dimes" offices to meet with representatives from Polio Canada. Sheila Casemore has been my email contact who's full title is: Group Development and Support Coordinator, National Programs, Ontario March of Dimes and Rehabilitation Foundation for Disabled Persons, Canada Stroke Recovery Canada and Polio Canada ([www.marchofdimes.ca](http://www.marchofdimes.ca) / [www.poliocanada.com](http://www.poliocanada.com)). Sheila introduced us to Polio Survivors, Jan Nichols, Chair, Toronto/York/Peel Post Polio Chapter and Elizabeth Lounsbury, Chair of Polio Canada, and we got down to the serious business of having lunch (which Sheila had thoughtfully arranged for us) and chatting.

Polio Canada was established approx 5 years ago in response to the growing need for PPS information and established contact points throughout Canada. Their charter is to support and inform the community and health care professionals through five main services. Polio Canada also provides a comprehensive information package on post-polio syndrome, free subscription to its bi-annual newsletter, local chapter newsletters and bulletins on news and events.

We spoke for some time on the subject of the soon to be established "Polio Australia's" ongoing communication with Polio Canada, Post-Polio Health International (see St Louis, USA), and other large networks in Britain and Europe with a view to forming "Polio World". This may sound a bit ambitious, but in the era of email and internet technology, there's no reason why we can't all become more cohesive. The purpose of such a union would be to try and co-ordinate our awareness campaigns and support each other through a united voice.

A significant issue was discussed regarding Ontario's only post-polio clinic being closed a few years ago, despite intensive lobbying by Polio Canada and polio survivors throughout the province, simply due to the hospital that was being funded to run the service deciding to pull out.

The message is repeated wherever we go, generic clinical service providers just don't know how to work with polio survivors without some kind of knowledge/training in the area.

Ontario March of Dimes has taken on a major role in the area of Stroke recovery and is slowly venturing into running joint support group activities with their polio and stroke clients. They all understand the differences in their respective disabilities/abilities, but both appear to be benefiting from these activities. We continued to discuss the potential for alliances in clinical service provision for a variety of groups ageing with a neurological condition.

Further to this lunchtime meeting, Sheila had suggested that we meet up again at 7.00pm at the Royal Ontario Museum (ROM) for an exhibition put together by Disability Studies students at Ryerson University called "Out From Under". One of the features of this exhibition depicted the story of a man by the name of Rev Essex, a Baptist Minister whose daughter, Sheila, contracted polio during the 1950's and was institutionalized due to her dependency on a respirator. Against medical advice, Rev Essex brought his daughter home, learning how to repair her equipment via telephone contact with the manufactures in the USA. A few years later, the 'cuirass' (a portable respirator) was introduced, further liberating his daughter. Rev Essex went on to volunteer his services by travelling around the countryside to fix respirators. Karen Yoshida, one of the contributors to this exhibition, is quoted as saying, "Through this work I have come to recognize how today's Independent Living Movement and its origins during the 1970 's were actually built upon unrecognized histories such as this."

All in all, we had an enjoyable and productive visit with the Polio Canada and Ontario March of Dimes people in Toronto and, once again, not enough time to further explore the city before heading off tomorrow by train to Ottawa. There, I'm looking forward to meeting up again with Dr Marcia Falconer, who we had speaking in Melbourne in 2006 about inflammation and PPS, as well as visiting with Dr Douglas McKim, Medical Director, Respiratory Rehabilitation Services, The Ottawa Hospital Rehabilitation Centre. More soon.

**Dr Marcia Falconer, Ottawa**  
**Saturday 24 May 2008**

Since arriving in Canada, I've had to come to terms with two things: one is that the cell phone I bought in LA from AT&T doesn't work here (something to do with it being 'locked'); and the other is that the bug I've been fighting off for the last couple of days has won. At the museum last night, I felt pretty ordinary and my voice was losing strength – not an occurrence I've had to deal with too many times in my life. Then when I called Jill this morning to discuss our breakfast arrangements, I found I had no voice at all. What came out was a whispered squeak. I have self-diagnosed laryngitis and hope it clears up in a day or so. Jill thinks it's rather amusing having to do all the talking for me.

The four hour trip on the train from Toronto to Ottawa (both in the province of Ontario) was pleasant but uneventful. We arrived around 4.30pm to be greeted by Marcia Falconer, who had kindly offered to pick us up and drive us back to our motel. It was a lovely day in Ottawa, which seemed to bring out every single resident in the whole city for something or other. The roads were absolutely clogged with cars being blocked from going where they wanted due to what had to be more than one major festivity. I recall it being difficult to even book accommodation for this weekend in the town – and that was several months ago. We are actually staying in the suburbs closer to Marcia for both this reason and to have ready access to her for a more structured discussion tomorrow.

This evening was just reestablishing contact in a more a social context, which was very pleasant. And, of course, there was dinner at the local Vietnamese restaurant. That was a real treat. Tomorrow we will be discussing Marcia's research in the area of inflammation and PPS. Stay tuned.

**Dr Marcia Falconer, Ottawa**  
**Sunday 25 May 2008**

It's always a delight to hear Marcia speak on her specialist subject of inflammation and its relationship to post polio syndrome (PPS). To recap, Dr Marcia Falconer is a polio survivor, as well as being a molecular biologist and virologist who led a government research laboratory in Ottawa, Ontario, Canada. She retired from active research in 2000 because of PPS, however she continues to follow new developments in the area of PPS such as neuroinflammatory processes and virology.

Marcia travels to Australia regularly to visit family in Sydney and has spoken on a number of occasions for the Post-Polio Network (NSW). In 2004 I went up to Sydney with Jill to see one of her talks and was so impressed, I communicated with her for the next 18 months to see if she could be enticed to come to Melbourne, which finally she did in May 2006 (see write up in Polio Perspectives Winter 2006: <http://www.polionetworkvic.asn.au/newsletters/items/2006/09/102206-upload-00001.pdf>).

However, today we did a lot of talking about how to decrease the chronic inflammation that plays such a major part in so many cases – including PPS. Marcia is her own test case regarding the efficacy of reducing inflammation via weight loss, diet, pacing and meditation. Although it took three years of observing a rigorous regime, Marcia believes her PPS symptoms have improved considerably. Interestingly, with a bit of knowledge and a lot of perseverance and willpower, these are all things that people can do for themselves. Marcia quotes from two books that she believes are extremely well written and researched called: “The Anti-Inflammation Zone” and “The Omega RX Zone”, both by Dr Barry Sears, which should be readily available in book shops or online through Amazon.

Marcia's ideal PPS clinic would be made up of physical therapists and orthotists for people with muscle weakness; and a specialist to work with inflammation, specifically in the area of stress reduction – both physical and emotional, but also diet. So this specialist role may be made up of one or a number of therapists such as an OT, nurse, psychologist, and nutritionist. However, Marcia places a caveat on the philosophy of nutritionist, believing it would need to be based on the low GI diet and not the traditional pyramid type. She says that many of the carbohydrates represented in the largest portion of the food pyramid can, in fact, exacerbate inflammation - and fat - if eaten according to the recommended portions.

With increasing research being done in the area of inflammation as a component of many illnesses such as diabetes, heart disease and arthritis, Marcia believes that the “inflammationologist” (a made up name) will have an important role in clinics of the future. She also believes there is a real place for additional/complementary therapies such as chiropractors, acupuncturists, naturopaths, aromatherapy and gentle yoga (or similar) to be used as an adjunct. Of course, they would also need to be aware of the specific pathophysiology of PPS, which polio survivors themselves may need to provide the education for.

There was so much more discussed during this session that the video tape ran out, but I captured most of it on my digital audio recorder. Hopefully, all these ideas will come together in a book (or two) in the not-too-distant future. We spent many hours at Marcia's lovely house, with her wonderfully green garden in full Spring bloom and black squirrels running all over the place. We even met her daughter and two granddaughters during the morning before being treated to lunch on the outside deck in the sunshine. Later that evening, Jill and I were taken out to an Indian restaurant for dinner by Marcia and her husband, David, which was very pleasant. Marcia said she had contemplated cooking us dinner but I'd had an allergic reaction to her two cats during the day and this, on top of my infection, made for a lot of tissue use.

We were driven back to the motel at around 9.00pm where it was time for Jill and I to say our farewells after five weeks of travelling together. Tomorrow I have an appointment with Respiratory Rehabilitation Services at The Ottawa Hospital Rehabilitation Centre before catching a train to Montreal, and Jill is catching a flight to the UK. It's odd to think that our joint adventures end here as those weeks seemed to have rushed by. And Marcia made the point that we were still talking to each other! All in all, I think we made a good team, with Jill adding her OT informed opinions to my observations – and we even enjoyed each other's company! So, it was with some emotion that we parted company. But only until she comes back to ParaQuad to report for voluntary work in a month or so.

## **Respiratory Rehabilitation Services at The Ottawa Hospital, Ottawa Monday 26 May 2008**

The wonderful Marcia offered to collect me in the morning (via Starbucks for a cappuccino) and drove me to my appointment with Dr Douglas (Doug) McKim, Medical Director, Respiratory Rehabilitation Services at The Ottawa Hospital Rehabilitation Centre ([www.ottawahospital.on.ca/rehabcentre](http://www.ottawahospital.on.ca/rehabcentre)). Respiratory treatment was not actually something I had considered as part of my original itinerary but when Joan Headley at Post-Polio Health International (PHI) pointed out this gap, it made sense to include such a service provider. One arm of PHI also deals specifically with ventilator users, and is called International Ventilator Users Network (IVUN) ([www.post-polio.org](http://www.post-polio.org)).

The percentage of people who experience respiratory and swallowing problems as a result of post polio syndrome (the two often go together due to the region of muscles affected by the initial polio infection) has been quoted at something like 12-15%. This number is not insignificant and may even be higher as many people may be undiagnosed. Symptoms of a respiratory condition may include sleep apnea, shallow breathing and shortness of breath, chronic headaches, dizziness or lightheadedness, and 'brain fog' due to a lack of oxygen.

Therefore, it is a very important area to cover and I was pleased to be provided with Dr Doug McKim as a contact by Joan. The Respiratory Rehabilitation Services at The Ottawa Hospital are reputed to be at the cutting edge of respiratory therapy and work with a number of Chronic Obstructive Pulmonary Disease (COPD) conditions such as ALS, Multiple Sclerosis, Muscular Dystrophy, and Post Polio Syndrome (PPS). The clinic was very busy in the morning when I arrived, and Doug introduced me to Carole LeBlanc, a Registered Respiratory Therapist (RRT) and COPD Educator. I advised both Doug and Carole that I was an absolute novice in the area and they took that on board when explaining the work they did. They even have a step-by-step education program for patients and their practitioners: <http://www.irrd.ca/education/slide.asp?RefName=e2r4&slideid=1>

The key point they wanted to make was that it is just as important to keep the airway supple as with other muscles and one of the best ways to do this is what they call "lung volume recruitment" (LVR). The two best ways to achieve this for a person with PPS is by the tried and true 'frog breathing' that many will recall from their childhood, or with a 'volume augmentation bag'. The bag is a simple device that incorporates a: resuscitation bag; 50cc tube; one way valve; one way valve with silicone valve removed; mouth piece; and a noise clip. There are various levels of this equipment available, but for PPS patients, the clinic recommends the best quality for daily use at a cost of something like \$260.00 Canadian dollars. When assembled, it the user would simply squeeze the bag 3 or 4 times to 'layer' the breath before breathing out and repeating this four times a day. The purpose of this is to: improve chest movement; prevent small areas of the lung from collapsing; improve cough; and increase speaking volume. The LVR method can be used by itself if the respiratory condition is not too problematic, or as an adjunct to a bi-level respirator if further intervention was required. For a full step-by-step explanation of this and other methods used, visit the Respiratory Rehabilitation Services at The Ottawa Hospital Rehabilitation Centre's Respiratory Care Protocols: Interventions webpage: <http://www.irrd.ca/education/presentation.asp?refname=e2r4>

During the afternoon, I was introduced to three polio survivors who were using the volume augmentation bag and most of the tests performed indicated that lung capacity had improved. Prior to being referred to Doug and the team, one woman had had a real problem recovering from a surgical procedure due to the treating hospital's lack of understanding of how her chest and abdominal muscle weakness would impact on her capacity to breath unassisted immediately following the operation. Another man said he had never experienced breathing problems until he had a car accident which left him with whiplash and triggered off his PPS symptoms, respiratory difficulty being part of the package.

This same man told me that, unfortunately, there are no polio support groups operating in Ottawa. Although the clinic is excellent at assisting polio survivors with their respiratory problems, there is no connection to services that can deal with other PPS problems. Discussion was also had regarding the general lack of doctors available in Ontario, with many people not having their own doctor – or at least a GP they could see as required. That would indicate to me that polio survivors in this Province at least (don't know enough about the rest of Canada) would have a tough time getting any information or adequate service provision for PPS.

I was certainly glad that I visited the Respiratory Rehabilitation Services and was stepped through the benefits of LVR. I'm sure this simple technique will be of great benefit to many people because it can be done quite independently and has proven results for polio survivors with respiratory conditions.

Doug was even kind enough to drive me to the train station where I will be catching a train to Montreal to spend time with my family over the next week. Official activities I will be doing whilst in Montreal include dining with Members of the Association Polio Quebec Board on Thursday evening; visiting the Montreal Neurological Institute and Hospital on Friday; and attending/speaking at the Association Polio Quebec's AGM on Saturday, just before I fly back to Australia. This means the next report may not appear for a few days. But I'll have plenty of time on the plane to catch up, I imagine . . .

**Dr Daria Trojan, Post Polio Clinic, Montreal Neurological Institute and Hospital, Montreal, Quebec**  
**Friday 30 May**

I was very pleased to have the opportunity to meet with Dr Daria Trojan, Physiatrist, whom I videotaped and with the assistance of Danielle Lafleur, the clinic Administrator, I was treated to a morning tea and information exchange with other members of the team. This was followed by one-to-one interviews with Dr Diane Diorio, Neurologist, as well as Marie-France Lanoie, the Physiotherapist, and Tatiana Ogourtsova, Occupational Therapist. People requiring other treatments are referred out to PPS-aware health professionals in the community. The OT on the team is responsible for the swallowing and cognitive difficulties that other PPS clinics may refer to a Speech Therapist.

I was also granted permission to observe two follow up assessments with Dr Trojan. These patients had been attending the clinic for many years and had nothing but praise for Dr Trojan and the other clinic staff. One woman had rejected an orthotic because it was grey instead of white and Dr Trojan made a point of saying that Montreal women were generally very conscious of their appearance, often wrapping scarves around their mobility aids to coordinate with their outfits. Very French!

The best way to describe the clinic is to quote directly from the web page for the Post Polio Clinic at Montreal Neurological Institute and Hospital:

“The post-polio clinic was started by Dr. Neil Cashman, Neurologist, in 1986. Dr. Daria Trojan, Physiatrist, joined the clinic in 1989 first as a research fellow, and then as a clinic physician. The clinic is currently coordinated by Dr. Trojan. Dr. Diane Diorio, Neurologist, joined the clinic in 2001. The work of the post-polio clinic encompasses three areas: 1) clinical care of patients, 2) education of health care professionals and lay groups, and 3) clinical research on post-polio syndrome.”

“To this time, more than 1000 post-polio patients have been evaluated. The referral base is primarily the province of Quebec, secondarily eastern Canada. A first appointment in the clinic involves evaluation by Dr. Diane Diorio or Dr. Daria Trojan. Many patients are followed regularly in the clinic, approximately every 6 to 12 months. Some patients are referred for electromyography (EMG) studies to Dr. Daniel Gendron. Many patients are referred to a pulmonary specialist with a special interest in neuromuscular disease at the Royal Victoria Hospital, and to other specialists, as necessary. Most patients are also referred to the physiotherapists and occupational therapists of the Montreal Neurological Hospital.”

“The post-polio clinic patient population provides volunteers for several ongoing clinical studies including studies on the relationship of fatigue with brainstem neuronal injury and other factors, and studies on determinants of adherence to treatment recommendations in patients with post-polio syndrome.”

Unfortunately, due to the fact that this is the only post polio clinic in Canada’s Eastern provinces, they are overwhelmed with patients and, consequently, experience the same up to six month waiting list that we have with Polio Services Victoria.

What is really outstanding about this post polio clinic is the clinical research it has generated over the years. Dr Trojan’s reputation precedes her as the result of a number of clinical research projects she has instigated and subsequently published articles on post polio syndrome-related issues, such as:

- Osteoporosis in a Postpolio Clinic Population (quoted from the Aug 2007 article, “Conclusions: In this retrospective, cross-sectional study, we found that osteoporosis and osteopenia at the hip occur commonly in postpolio clinic patients referred for bone densitometry in men, premenopausal women, and postmenopausal women compared with the general population.);

- Sleep-Disordered Breathing in Fatigued Postpoliomyelitis Clinic Patients (quoted from the Oct 2006 article, “Conclusions: In our retrospective, cross-sectional study, we found that SDB, especially obstructive hypopnea, was very prevalent among postpolio clinic patients referred for sleep evaluation.”);
- Predictive Factors and Correlates for Pain in Postpoliomyelitis Syndrome Patients (quoted from the Aug 2002 article, “Conclusion: Our study provides insights on the pathophysiology and possible management of muscle and joint pain in PPS . . . Because pain is associated with significant reduction in Quality Of Life in PPS, further study of this important symptom is indicated.);
- A multicenter, randomised, double-blinded trial of pyridostigmine in postpolio syndrome (unfortunately, the 1999 article concluded that “This trial did not show a clear benefit of pyridostigmine.”);
- Fibromyalgia Is Common in a Postpoliomyelitis Clinic (quoting from the June 1995 article, “Conclusions: (1) Fibromyalgia occurs frequently in a postpolio clinic. (2) Fibromyalgia can mimic some symptoms of postpoliomyelitis syndrome. (3) Fibromyalgia in postpolio patients can respond to specific treatment.”)

Dr Trojan has also just completed another study to compare inflammatory markers in PPS patients to normal controls. The study also included MS patients with PPS patients, and normal controls. They have presented the MS inflammatory marker results (with the PPS and normal control results) in abstract form but not in the published paper.

Dr Trojan believes this study needs to be further developed by other scientific researchers. However, referring to discussions with Dr Marcia Falconer (see Ottawa), if proven, this could be significant in supporting the theory of inflammation playing a part in postpolio syndrome. As a respected and measured researcher, Dr Trojan is careful not to draw any such conclusions from her own study. But as an enthusiastic Community Development Worker, I’m quite happy to speculate . . .

For anyone wanting to read more about the research mentioned above, Dr Trojan has provided me with the articles, which can be accessed through the Polio Network Victoria’s library. Of course, they are all subject to Copyright. Some of these studies may be available to read on-line through Post-Polio Health International (PHI – see St Louis).

I found my visit to the Post Polio Clinic at Montreal Neurological Institute and Hospital very informative and valuable in adding yet another perspective to the range of services that can assist polio survivors. If only we could blend the best aspects of these post polio clinics for the benefit of all. Ah, well – it can’t hurt to dream.

## **Association Polio Quebec, Montreal / End of Trip Thursday 29 & Saturday 31 May**

Mr Gilles Besner is the President of Association Polio Quebec and, after we had been emailing about my visit for a few months, he invited me to attend a dinner with the Board on the Thursday evening before giving a presentation at their Annual General Meeting on Saturday 31 May – the day I was flying back to Melbourne. I was delighted to accept both invitations, especially as my flight on Saturday wasn't leaving until 5.30pm and it's so boring just waiting around all day before going to the airport.

According to their website ([www.polioquebec.org](http://www.polioquebec.org)):

The vision of the Polio Québec Association is to be the best possible source of help in Québec for people affected by polio. Its mission is to provide support and information to those who had polio and to foster public awareness on all aspects of polio, including prevention. Its goals are to:

- Foster public and medical awareness about polio, post-polio syndrome and the importance of measures which improve the quality of life;
- Advocate on behalf of people who had polio;
- Develop and strengthen partnerships with other relevant organizations;
- Encourage research into the treatment of post-polio syndrome and other related conditions.

Dinner on Thursday took place at a suburban Italian restaurant which my uncle dropped me off at and which Gilles and his wife had offered to drive me back from. There were around 14 members of the Board present, made up of polio survivors and 'interested others' such as treating physicians and family members. One such member was Stewart Valin, the son of a polio survivor and co-editor of a book entitled "Walking Fingers": The Story of Polio and Those Who Lived With It. The title describes how Stewart's father used to reach for items across the dining table with his polio-weakened arms. The other co-editors are Sally Aitken and Helen D'Orazio. "Walking Fingers" was presented to as a gift to be added to the polio library. I am very much looking forward to reading it, as well as identifying any ideas we might like to borrow for our own Oral Polio History book project. The book is available on line through Amazon: [www.amazon.com/Walking-Fingers-Story-Polio-Those/dp/1550651803](http://www.amazon.com/Walking-Fingers-Story-Polio-Those/dp/1550651803)

As well as Gilles, there were also 2 previous Presidents of Association Polio Quebec present. I was sitting opposite Dr Daria Trojan, with whom I was scheduled to meet with on Friday morning. The discussion around the table was mainly about the similarities Canada and USA have with Australia regarding the numbers of polio survivors still seeking information and lack of government funding available for resources and services.

After dinner, Gilles and his wife drove me through Montreal's CBD to see it by night. We also travelled to the highpoint, Mount Royal, to look out across the lights of the city. It was a lovely sight, if just a little too chilly for my still infected bronchial system. As with this type of location everywhere in the world, many young people were busy finding all kinds of ways to keep warm. We continued on down one of the main thoroughfares, St Catherine Street, which, at some point, becomes Montreal's 'gay quarter'. Montreal has the reputation of being one of the most liberal minded provinces concerning the gay movement and people come from all over Canada, as well as the USA, to enjoy this freedom of expression.

Association Polio Quebec's Annual General Meeting was held on Saturday at one of Montreal's hotels on a dank and rainy day. The weather may have impacted on the number of people who were expected to attend but there were still something like 20-30 present – including 2 of my uncles, one of whom is a professional photographer, so we should have some quality shots of the day in due course.

My presentation provided a history of the Polio Network as a service of ParaQuad Victoria and how we and the other Australian networks are looking to form Polio Australia to establish a national voice.

I reiterated the need for our type of organisations to continue providing information and, if possible, to incorporate an active outreach program for all those polio survivors who still haven't heard of post-polio syndrome.

Being in Montreal, Quebec, the audience was predominantly French speaking, but one of the Board members (a physiotherapist) was kind enough to provide the translation. I was actually born to a French-Canadian mother and all that side of my family is French speaking. However, due to our migrating to Australia when I was a baby – and with my father being Dutch – regrettably, I was never taught the language myself. Many Quebecois can speak both French and English, but there are also many who do not. All signs are in French and you really know you are in a different part of the country – virtually and separate country in itself. There is a long and complex history of conflict between the English and French settlement of Canada dating back to the 1500-1600's. If the difference in monarchy, language, and culture isn't enough there is also the Protestant (English) vs Catholic (French) religious tension. All very interesting and perplexing for an 'outsider' like me.

Then it was time to go and I was presented with a plaque of appreciation, which I just managed to squeeze into my luggage. My uncle drove me to the airport for the first of the three flights I had to catch back to Melbourne, i.e. Montreal to Chicago to Los Angeles to Melbourne. As I write this, I'm still waiting for my luggage to catch up to me. The suitcase and I lost contact at LA and it somehow found its way to Brisbane before being put on another plane back to Melbourne. Better the bag than me, but there are a number of things I'm keen to be reunited with – including the "Walking Fingers" book, 4 cans of maple syrup, and some necessary items of clothing . . . Some stuff I could easily replace – other items are irreplaceable simply due to the nature of how I acquired them.

So, the six week trip has come to an end and I have yet to integrate all that I have learned. However, I feel more confident that Polio Network Victoria is really doing as much, if not more, than other information-based organisations throughout the USA and Canada. I can only hope the information exchange has also benefited some of the people and organisations I have visited. A full report will now need to be written for the Churchill Trust which will also be uploaded to the Polio Network Victoria website. A copy of the report will also be provided to all those people and organisations I visited. Many people were videotaped and/or audio taped which will also need editing. In other words, there's still a lot of work to do, so wish me luck!