

The Winston Churchill Memorial Trust of Australia

Report by: MARY-ANN LIETHOF – 2007 Churchill Fellow

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

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Introduction

The purpose of my study tour was **“To identify techniques to better manage the late effects of polio”** in the USA and Canada.

The inspiration for this project was born out of witnessing the courage and determination revealed to me on a daily basis by the ‘community’ of polio survivors I work with, who are now experiencing post polio syndrome (PPS).

Therefore, it is the post-polio community I would first like to acknowledge, along with my travelling companion, Jill Pickering, herself a polio survivor. Jill’s insight as both a trained Occupational Therapist (now retired) and someone living with PPS, proved to be invaluable on my study tour.

I must also acknowledge ParaQuad Victoria and my fellow workers who supported me in my six week absence from the workplace.

The many and varied places visited provided me with a wealth of information on current PPS management techniques provided by individuals and teams of specialists. Everyone I had the privilege of meeting was very welcoming, helpful and generous in imparting their knowledge. I thank them all.

I am honoured to be a recipient of the 2007 Churchill Fellowship who provided the means to achieve my goal and will fondly remember the ‘once in a lifetime’ opportunity the Churchill Trust has provided.



Executive Summary

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Project Description:

As there are limited services for polio survivors, and no Post Polio Syndrome (PPS) research is currently being carried out within Australia, the overall purpose of this study tour to the USA and Canada was to:

- identify the latest research being carried out into the cause and management of PPS symptoms
- observe a variety of 'best practice' services for polio survivors
- learn about the range of resources and equipment available
- enhance understanding of the wider implication of emotional and psychological issues that impact on polio survivors and family members
- open up networks and links with clinicians for Polio Services Victoria to pursue

The range of individuals and institutions visited more than fulfilled all these criteria, making it very difficult to pick out specific highlights.

Highlights:

- The incredible dedication of Dr Jacquelin Perry and range of facilities available at Rancho Los Amigos
- The historical significance of Roosevelt Warm Springs Institute for Rehabilitation
- The holistic approach to wellness being practiced at John P Murtha Neuroscience and Pain Institute
- The youthful team at Spaulding Rehabilitation Hospital's long-term commitment to provide ongoing services for polio survivors
- The valuable clinical research being conducted by Dr Daria Trojan at Montreal Neurological Institute and Hospital

Major lessons and conclusions learnt are:

- The most effective way of managing PPS symptoms and ensuring polio survivors remain as active and independent as possible is through self-management techniques coupled with regular specialist clinic assessments and intervention strategies.
- Services for polio survivors will be required for at least another 20-30 years.
- Services are merging PPS with other neurological disorders in order to attract funding to continue service provision.
- The apparent lack of active community outreach to younger polio survivors who may be unaware of PPS is reflected in the decline of support groups in the USA/Canada.
- There very few clinics/institutes/individuals doing PPS research.

Information Dissemination:

- Daily reports & photos were uploaded onto the Polio Network website: www.polionetworkvic.asn.au / Churchill Fellowship Study Tour, which will remain for approx 12 months.
- Over the next few weeks/months, I will be working on distilling the volume of information received in a presentation format that can be shared at the eight regional Polio Days during Victoria's Polio Awareness Month in October 2008.
- I have also been invited to share this presentation with the Queensland, Tasmanian and New South Wales Post-Polio Networks in August, September and November, respectively.
- This report will be distributed to: all clinics/individuals visited; all Victorian polio support groups; Australian interstate and New Zealand Post Polio Networks; uploaded to Polio Network website.
- Videotaped interviews will be edited and compiled into a DVD to be distributed as above.

Programme

Los Angeles, California, USA – April 20 to 26, 2008

- Mr Richard Daggett, President, Polio Survivors Association
- Los Angeles Post Polio Support Group
- Dr Susan Perlman, Director, Post-Polio Clinic, University of California, Los Angeles (UCLA) Medical Center and Melinda Guttry, Physical Therapist, UCLA Rehabilitation Services
- Dr Sophia Chun, Chief and Dr Jacquelin Perry, Consultant, Post-Polio Service, Rancho Los Amigos National Rehabilitation Center

St Louis, Missouri, USA – April 26 to 29, 2008

- Ms Joan Headley, Executive Director, Post-Polio Health International (PHI)
- Paraquad Inc.

Warm Springs, Georgia, USA – April 29 to May 3, 2008

- Mr Greg Schmieg, Executive Director and Mr Michael Shadix, Librarian/Historian, Roosevelt Warm Springs Institute for Rehabilitation
- Roosevelt's Little White House & Historic Hydrotherapy Pools

Washington, DC, USA – May 3 to 8, 2008

- Dr Lauro S. Halstead, Director, Post-Polio Program, National Rehabilitation Hospital (editor of Managing Post-Polio: A Guide to Living and Aging Well with Post-Polio Syndrome)
- Ms Wendy Wilmer, President and Mr Elver Ariza, Board Member, The Polio Society
- FDR Memorial

Johnstown, Pennsylvania, USA – May 8 to 11, 2008

- Ms Barbara Duryea, Director, Research and Development & Dr William M DeMayo, Medical Director, Post-Polio Center, John P Murtha Neuroscience and Pain Institute

New York, NY, USA – May 11 to 19, 2008

- Dr. Richard L. Bruno, Director, The Post-Polio Institute and International Centre for Post-Polio Education and Research (New Jersey) (author of The Polio Paradox)
- Ms Susan Fish, Physical Therapist
- Dr Margaret E Backman, Clinical Psychologist (author of The Post Polio Experience: Psychological Insights and Coping Strategies for Polio Survivors and Their Families)

Framingham, Massachusetts, USA – May 19 to 22, 2008

- Dr Darren Rosenberg, Medical Director and Ms Anna Rubin, former Education and Outreach Coordinator, Spaulding Rehabilitation Hospital

Toronto, Ontario, Canada – May 22 to 24, 2008

- Ms Sheila Casemore, Group Development and Support Coordinator, National Programs, Ontario March of Dimes and Rehabilitation Foundation for Disabled Persons / Polio Canada
- Ms Jan Nichols, Chair, Toronto/York/Peel Post Polio Chapter and Ms Elizabeth Lounsbury, Chair of Polio Canada

Ottawa, Ontario, Canada – May 24 to 26, 2008

- Dr Marcia Falconer, Virologist and Researcher
- Dr Douglas McKim, Medical Director and Ms Carole LeBlanc, Registered Respiratory Therapist (RRT) and COPD Educator, Respiratory Rehabilitation Services, The Ottawa Hospital Rehabilitation Centre

Montreal, Quebec, Canada – May 26 to 31, 2008

- Mr Gilles Besner, President and Ms Mado Shrivell, Secretary, Association Polio Quebec
- Dr Daria A Trojan, Director, Post Polio Clinic, Montreal Neurological Institute and Hospital

The Experience

Los Angeles, California, USA

- **Polio Survivors Association** (www.polioassociation.org)



Jill Pickering, Mary-ann, Richard Daggett & Nora

Richard Daggett is the President of the Polio Survivors Association and Editor of the Rancho Los Amigos Post-Polio Support Group Newsletter. 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. In typical polio style, he is a very busy man, although he still found the time to pick us up in his low floor, modified people mover driven by Nora, one of his 5 support workers.

We were invited back to Richard's home where he showed us a number of photos and presentations on his computer. One was a photo of Richard shaking hands with polio vaccine founder, Dr Jonas Salk, whom he had met in the 1980's. By all accounts, Salk was a very pleasant man.

Richard had offered to book our accommodation at a place called H.O.M.E. (Housing Of Medical Emergencies), which 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 paid. 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 had our appointments.

The Experience

Los Angeles, California, USA (cont'd)

- **Los Angeles Post Polio Support Group Meeting**

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.

We were collected by Richard and driven a few miles away to 'County Orange' to meet up with 8 post polio support group members for lunch. 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 patchy historical record keeping on the subject, I had no ready answers. I have not 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 C-PAP machines at night to assist with sleep apnea. There has also been some discussion regarding the use of a bi-level respirator. Where the C-PAP 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 (as with many polio survivors) have difficulty actually breathing out against this pressure. The bi-level is designed to give a certain pressure when breathing in and reduced pressure when breathing out. This is something worth following up in Australia.

- **Key Point:**

- Promote discussion between ventilator users and their doctors regarding the use of bi-level respirators versus C-PAP.



Members of the Los Angeles Post Polio Support Group

The Experience

Los Angeles, California, USA (cont'd)

- **University of California, Los Angeles (UCLA) Medical Center** (www.healthcare.ucla.edu / Medical Services / Neurology)

Dr Susan Perlman is the Director of the Post-Polio Clinic and Clinical Professor of Neurology, Neurogenetics Clinic, UCLA Neurological Services and Melinda Guttry is a Physiotherapist with UCLA Rehabilitation Services.



Dr Susan Perlman and Melinda Guttry, PT

Dr Perlman discussed 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 way across town (25 miles) and the numbers emerging at that time seemed to warrant an additional service.

Clinic Structure

Luckily, Dr Perlman became interested enough in PPS to do more research on the various symptoms and had access to the full compliment 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.

Dr Perlman has 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.

Dr Perlman believes 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.

- **Key Points:**
 - Monitor research developments are in the areas of 'inflammatory markers' and the immune treatment 'intravenous immunoglobulin' (Ivlg).
 - Polio survivors must become self-educated regarding PPS, then to educate their own health service providers.

The Experience

Los Angeles, California, USA (cont'd)

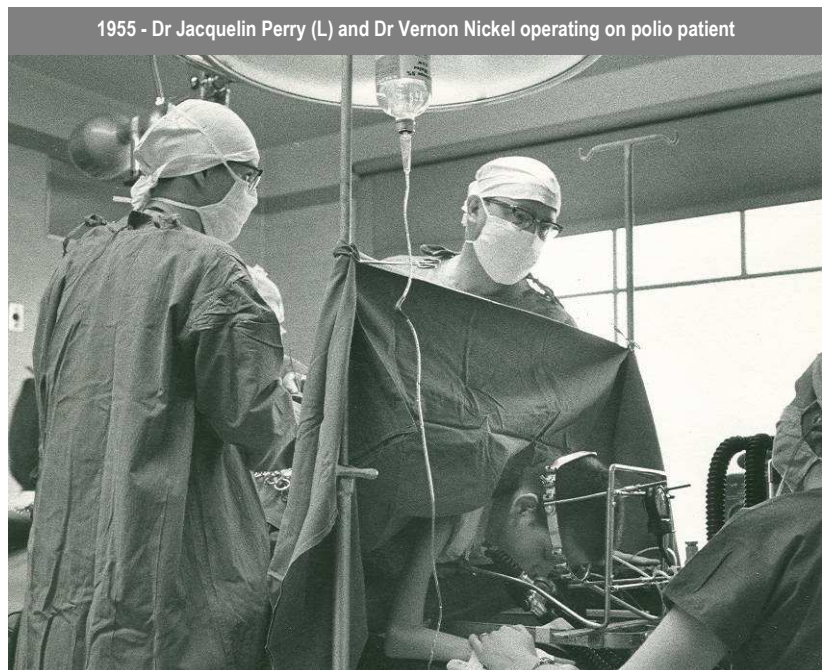
- **Rancho Los Amigos National Rehabilitation Center** (www.rancho.org/ser_postpolio.htm)
Richard Daggett arranged for us to look around the Rancho Los Amigos Rehab Center. He introduced us to a number of people at the volunteer center, one of whom had fond memories of visiting Australia.

We then went 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 chord injuries treated at Rancho are caused by shootings among gang members.

A meeting took place with Jan Furumasu, a physical therapy instructor working in the Seating Center. The majority of people being seen at the Seating Centre would be those with spinal chord 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 chord 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.

We then met with Molly Doyle, the Program Director for the Center 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 also showed us 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.

Our next appointment was 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. 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.



The Experience

Los Angeles, California, USA (cont'd)

- **Rancho Los Amigos National Rehabilitation Center (cont'd)**

She is very passionate about her work, still consulting in her 90's. 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 continues to see 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 have a great deal of respect for each other's contribution to the polio community.

Clinic Structure

Dr Sophia Chun 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.

Rancho's particular focus is on muscle function and overuse of particular muscle groups. They have 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. People with respiratory conditions are referred to Rancho's excellent Pulmonary and Critical Care Medicine Center, part of The Department of Medicine.

When asked about her thoughts on any promising research such as Ivlg, 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 the polio's had proceeded to overwork those newly 'strengthened' muscle groups. In other words, as far as this clinic is concerned, the only successful treatment for PPS is to PACE. 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."

It was interesting to note the difference in approach by the physiatrist vs neurologist (Dr Perlman, UCLA Medical Center) but there was no doubt that all techniques used were of benefit to their polio patients.

- **Key Services/Points:**

- Seating Center
- Center for Applied Rehabilitation Technology (C.A.R.T.)
- Pathokinesiology Laboratory
- Community based physicians/health workers should be knowledgeable about post polio syndrome and/or be willing to communicate with post polio specialists.
- Care should be taken not to overuse vulnerable muscle groups. In the words of Dr Perry, "Be an 'Intelligent Hypochondriac' – Listen to your body and adopt a program that avoids the strain."

The Experience

St Louis, Missouri, USA

- **Post-Polio Health International**

(www.post-polio.org)

Joan Headley is the Executive Director of Post-Polio Health International (PHI). 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 manufacturers. PHI also publishes a quarterly newsletter, compiles the Post-Polio Directory listing post-polio health resources and polio support groups around the world, maintains a website that averages 50,000 hits per month, and funds research projects including the latest “Regulatory T Cells as a Biomarker of Post-Polio Syndrome” being conducted at the University of Arkansas for Medical Sciences.



As indicated in their newsletter, Post-Polio Health, Spring 2008, Vol. 24, No. 2: “The ability of a physician to diagnose a specific disease can be significantly aided by the availability of one or several disease biological markers (termed biomarkers). No biomarker(s) has (have) been identified for PPS as yet that could assist in providing a definitive, easy and rapid diagnosis.”

- **Key Services/Points:**

- PHI annually funds research projects. It will be interesting to monitor results for “Regulatory T Cells as a Biomarker of Post-Polio Syndrome”.

- **Paraquad Inc.** (www.paraquad.org)

Joan is also on the Board of Paraquad Inc., a Center for Independent Living. 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 favourite – Recycled Durable Medical Equipment.

The Experience

St Louis, Missouri, USA (cont'd)

- **Paraquad Inc. (cont'd)**

To quote from their brochure, the Recycled Durable Medical Equipment program “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!

- **Key Services/Points:**

- Paraquad Inc.'s Recycled Durable Medical Equipment program “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”. Profits go back into the program.
- Paraquad Inc. has a strong relationship with Washington University (Missouri campus) and can utilise the services health-related students in areas such as occupational therapy and research.



The Experience

Warm Springs, Georgia, USA

- **Warm Springs Institute for Rehabilitation** (www.rooseveltrehab.org)

Greg Schmieg, the Executive Director of Roosevelt Warm Springs Institute for Rehabilitation met us 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 bares 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."*

"The Polio Hall of Fame" consists of 17 bronze busts depicting 15 scientists and 2 laymen who were instrumental in the fight against polio – sculpted by Edmond R Amateis. We were also told that funding had been received from Rotary International's Polio Plus Program for these 17 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.



We viewed the "Smithsonian at Roosevelt Warm Springs: Whatever Happened to Polio?" exhibition with a sign above the door reading "Contagious Entrance". Apparently, many school children 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.

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.

Warm Springs also has an extensive Vocational Rehabilitation Unit, Therapeutic Recreation & Fitness, the totally accessible Camp Dream, and Conference Services. 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.

The Experience

Warm Springs, Georgia, USA (cont'd)

- **Warm Springs Institute for Rehabilitation (cont'd)**

Today Medical Services include: Long Term Acute Care; Inpatient Rehabilitation; and Outpatient Services such as Post-Polio Services, Acupuncture, Aquatic Programs, Diabetic Foot Center, Rehabilitation Technology, Seating and Wheeled Mobility Clinic, and Wound Care.

Clinic Structure

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.

The newly opened "Blanchard Hall" is 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'. 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. On an annual basis, there are approximately only 100 polio survivors seen at Warm Springs these days, many for orthotics.

I spent time with Mike Shadix 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.



FDR & Mary-ann at Dowdell's Knob

Greg later took us to 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. We were able to 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. 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.

The Experience

Warm Springs, Georgia, USA (cont'd)

- **Warm Springs Institute for Rehabilitation (cont'd)**
- **Key Services/Points:**
 - The “Roosevelt Way” is explained as an effective ‘hands on’ approach that Warm Springs has to physical therapy.
 - All braces are made 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.
 - 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.
- **The Little Whitehouse and Historic Hydrotherapy Pools** (www.fdr-littlewhitehouse.org)

The Little Whitehouse certainly lived up to its name. With the trend for huge, impressive buildings these days, it was interesting to see just how modestly a President could live.

The historic hydrotherapy pools was 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.

The Experience

Washington DC, USA

- **The Polio Society** (www.poliosociety.org)

We met with Wendy Wilmer (President) and Elver Ariza (Board Member) from The Polio Society. 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. She 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. Wendy got involved with The Polio Society because she is a keen advocate for disability rights and became the President in 2007.

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. 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. 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.

Key Points:

- 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.
- There are still many younger people, and those who are experiencing symptoms but are unaware that PPS even exists, who will need to access information and resources in years to come.

The Experience

Washington DC, USA (cont'd)

- **Post-Polio Program, National Rehabilitation Hospital**

Dr Lauro S Halstead is the Director of NRH's Post-Polio Program. In 2006, he printed the 2nd edition of "Managing Post-Polio: A Guide to Living and Aging Well with Post-Polio Syndrome" – 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.

Dr Halstead underwent numerous tests with a number of specialists, 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 to 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."



Ginger Stewart Walls, PT & Dr Lauro Halstead

With his medical background and personal experience, Dr Halstead was clearly an ideal physician to head the Post-Polio Clinic at the National Rehabilitation Hospital 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 member's 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.

The Experience

Washington DC, USA (cont'd)

Post-Polio Program, National Rehabilitation Hospital (cont'd)

Clinic Structure

The Post-Polio Clinic which includes consultations with Dr Halstead, a Physiotherapist, Occupational Therapist, Nurse Evaluation, Orthotist (if required), Electromyogram (EMG/muscle test) (if needed), and a Social Worker is conducted over 1½ days, the theory being 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. I can only assume people comply with the suggestions made and actually improve somewhat after such a thorough going-over.

Later, Dr Halstead and I discussed numerous aspects of the workings of NRH's Post-Polio Clinic, including the 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. Unfortunately, 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.

Key Services/Points:

- Independence Square
- Adaptive Driving Simulation
- Talking with other polio survivors at a support group facilitated the grieving process for the body lost 30 years earlier
- The Clinic is held over 1 ½ days to give people time to reflect
- 'Significant others' are encouraged to attend the final clinic assessment meeting
- Currently there is no successor to take on the role when Dr Halstead retires

FDR Memorial

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 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.



The Experience

Johnstown, Pennsylvania, USA

- **John P Murtha Neuroscience and Pain Institute** (www.conemaugh.org / Patients and Visitors / Conditions and Disorders / Post-Polio)

Dr William DeMayo, the Medical Director, provided an overview of the Specialty Clinics he manages including the Post-Polio Program. Other Neuroscience Specialty Programs include:

- Blending Traditional Medicine with Complementary Healing Methods to Treat PPS
- 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

There are also a number of interesting research projects that have been undertaken and others that are still works in progress. 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."

A monthly teleconference called the "Post-Polio Clinics Directors Network" is hosted by Dr DeMayo, which anyone with an interest in the subject can join (6.00 pm USA eastern standard time, third Tuesday of each month / 8.00am Australian eastern standard time, third Wednesday of each month). Many international organisations participate and I believe it to be a great initiative to promote in Australia.

Clinic Structure

It became evident 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 to achieve wellness.

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.

Jan Goodard discussed her work 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 it's not the smell that makes the oils work. Although skeptical, Jill later tried one of these oil blends for pain and was surprised and relieved by its efficacy.

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.

The Experience

Johnstown, Pennsylvania, USA (cont'd)

- **John P Murtha Neuroscience and Pain Institute (cont'd)**

Barbara Duryea, Director of Research and Development, was my main contact at JPMNPI. She put together an entertaining and informative presentation which took us through the JPMNPI experience before opening up to a general information exchange around the table. It was also an opportunity for the other staff members present to learn more about/refresh their knowledge of what's going on in their own workplace.

We were given a 'gift pack' containing 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 already have but one I haven't, called "Living with Polio: The Epidemic and its Survivors" by Daniel J Wilson.

In summary, John P Murtha Neuroscience and Pain Institute has been an absolute treat to visit. I was 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.

- **Key Services/Points:**

- Blending Traditional Medicine with Complementary Healing Methods to Treat PPS
- Exciting research Projects:
 - ~ Cognitive Function Status in Polio Survivors with and without PPS (not completed); and
 - ~ Hatha Yoga and Meditation in Patients with PPS (completed)
- Post Polio Registry Kiosk which is designed to track polio survivors and their health issues on-line
- Polio patients are given an "Osteoporosis Evaluation Score Sheet" to determine if follow-up was required during initial assessment
- Therapeutic Uses of Essential Oils
- Overall treatment of the body, mind and spirit is necessary for total wellbeing



Staff photo by Michael Kuhne

Australian visitors

Dr. William Demayo, director of the neuroscience specialty clinic, talks with Australian visitors Maryann Liethof, a community development worker, and retired occupational therapist and polio survivor Jill Pickering at the John P. Murtha Neuroscience and Pain Institute in Richland Township. Liethof and Pickering were provided with funding to go on a study tour in the United States and Canada. Their goal is to identify the latest research in managing post-polio symptoms and learn about the resources and equipment available.

The Experience

Englewood, New Jersey, USA

- **The Post-Polio Institute** (www.postpolioinfo.com)

Dr Richard L Bruno is the Director of The Post-Polio Institute and 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.” Dr Bruno wrote “The Polio Paradox” which works on this principle.



Dr Richard L Bruno

Clinic Structure

Dr Bruno 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 due to the possibility of unpleasant memories of the past. 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 contracted 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.

Immunisation

Dr Bruno also works to keep 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.”

The Experience

Englewood, New Jersey, USA (cont'd)

- **The Post-Polio Institute (cont'd)**

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.

- **Key Services/Points:**

- Psychology is required to reprogram the habits of a polio survivor's lifetime from overworking/overachieving to regulating their pace to match their energy capacity
- It is important for people to eat a proper diet and ensure they get enough protein to strengthen the muscle – especially in the morning
- More than one million US children are unvaccinated for polio
- There are many Western world polio survivors who are still only in their 40's, as well as people in countries where polio is still prevalent, who will need clinical services for years to come
- There are many more polio survivors experiencing PPS than those who have known how and where to seek advice, so public awareness campaigns are still required
- Dr Bruno has no successor, meaning this clinic will probably close when he retires

The Experience

New York, New York, USA

▪ **Susan Fish, Physical Therapist**

Susan was recommended as an interesting person for me to see via Dr Margaret (Peggy) E Backman. 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. 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 rarely happens because of the out-of-pocket cost of approx. \$120 per session. Although Susan only works with 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.

Devising an effective exercise program for PPS can be difficult to achieve, and Susan has seen the effects of both overworking AND underworking 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 interested to learn about my experience of what other innovative yet practical things individuals and institutes are doing. This discussion highlighted the fact that, in this day and age, information can be readily shared through email contact. 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'.

Susan is now only working part-time with a view to retiring in the not too distant future. As a sole practitioner, Susan has no successor/s with her level of expertise, leaving New York bereft of PPS specialists.

Key Points:

- There are no PPS clinics in the whole of New York
- PT's need to understand the limitations caused by polio's motor neuronal damage
- 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'
- Susan's impending retirement will leave NY with no PPS Physical Therapy specialists



Susan Fish, PT

The Experience

New York, New York, USA (cont'd)

- **Dr Margaret E Backman (Peggy), Clinical Psychologist**

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."

Peggy's involvement with post-polio really started in the early to mid 80's. She had a female client who came to see her with all kinds of information she had found 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.

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 are increasingly 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 one subscribes 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.

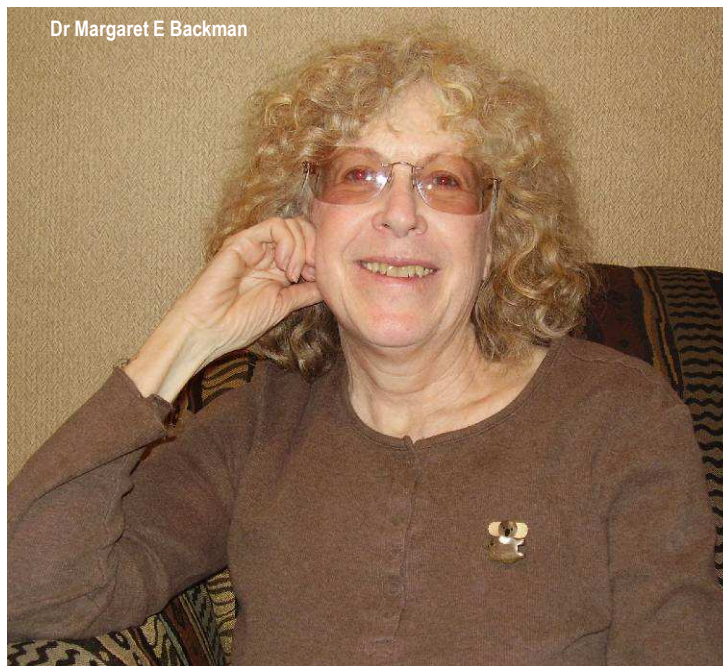
The Experience

New York, New York, USA (cont'd)

Dr Margaret E Backman (Peggy), Clinical Psychologist (cont'd)

Key Points:

- Doctors should be given a small brochure to introduce them to PPS
- A list of questions to ask during an appointment avoids wasting both the patient's and the doctor's time
- The ageing process appears to be the most troubling aspect for people
- It is important that the polio patient understands that a referral to a psychologist doesn't indicate that the doctor thinks it's "all in their head"
- The role of the family and 'significant others' is vital in supporting the polio survivor to cope with progressive changes in lifestyle
- Any 'stressors' should be addressed in order to relieve symptoms of PPS
- When Peggy stops practicing, "The Post-Polio Experience" will be her ongoing legacy



The Experience

Framingham, Massachusetts, USA

- **Spaulding Rehabilitation Hospital Network, Framingham**

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

Medical Director, Dr Darren Rosenberg's 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. The 'youthful' Dr Rosenberg believes 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.

Because of his skills specialty, 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 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.

Anna Rubin and Liz McKenney are the prior and current Co-ordinators of the IRCP at Spaulding. Anna and Liz provided 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 but these are not connected to the clinic apart from accessing services.

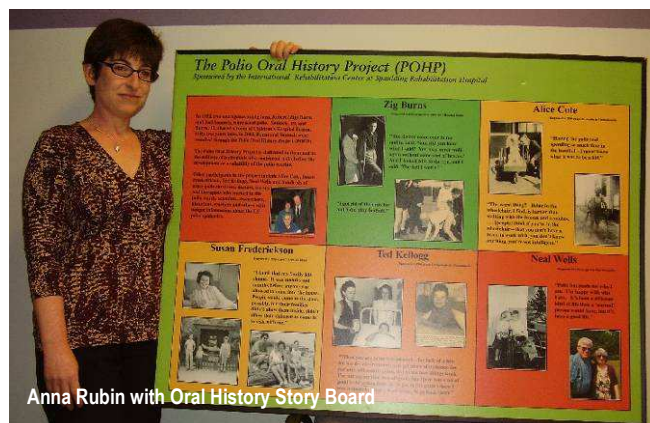
There is an educational component to the role insofar as giving talks at Rotary and other community meetings to which they are invited. Spaulding runs a school program which focuses on general disability awareness called "In My Shoes". This is a 2 day program which also incorporates a polio survivor talking about his/her own experience.

However, the main thrust of the Co-ordinators' 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.

The Experience

Framingham, Massachusetts, USA (cont'd)

- Spaulding Rehabilitation Hospital Network, Framingham (cont'd)



A key interest I had in talking with Anna was about her involvement with the "Oral History Project", the basis of previous Medical Director Julie K Silver's, book called "Polio Voices: An oral history from the American polio epidemics and worldwide eradication efforts", published in 2007 and co-authored with Daniel Wilson, PhD.

This was a four year project which 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 also instigated 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.

Robert (Bob) Drillio 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. For someone only requiring a bit of additional support we both liked a lightweight ankle-foot orthosis used for drop foot called "Foot-up": 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.

Psychologist, Dr Stephanie Machell, 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: 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.

Speech Therapist, Carolyn Balinskas, works with swallowing disorders, as well as sleep apnea, and cognitive fatigue. 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.

The Experience

Framingham, Massachusetts, USA (cont'd)

▪ Spaulding Rehabilitation Hospital Network, Framingham (cont'd)

Clinic Structure

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

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.

The Experience

Framingham, Massachusetts, USA (cont'd)

- **Spaulding Rehabilitation Hospital Network, Framingham (cont'd)**

- **Key Services/Points:**
 - Dr Rosenberg believes there will still be a need to provide services for post-polio patients through to his retirement
 - All staff have prescribed reading from books that provide a framework for the experience of a polio survivor
 - Manipulation has assisted post polio patients in freeing up motion and ambulation, helping with breathing problems, providing pain relief, and increasing tolerance for bracing
 - There is scope to incorporate people with other neurological conditions such as Parkinsons Disease, MS, etc. into the polio program
 - The “Oral History Project” was a 4 year project recruiting polio survivors from all over the USA
 - All therapists involved in an assessment meet together with the patient and any ‘significant other’ to discuss the process
 - Staff believe their sole objective is to assist the patient to achieve their own goals, backed up by the philosophical belief that the patient is the ‘expert’ on their own body
 - This team is young, motivated, stable, and committed to ensuring their post polio patients have access to skilled clinical services into the future

The Experience

Toronto, Ontario, Canada

- **Polio Canada / Ontario March of Dimes** (www.marchofdimes.ca / www.poliocanada.com)
Sheila Casemore is the Group Development and Support Coordinator, National Programs at Ontario March of Dimes and Rehabilitation Foundation for Disabled Persons Canada, Stroke Recovery Canada and Polio Canada. Sheila also introduced us to polio survivors, Jan Nichols, Chair, Toronto/York/Peel Post Polio Chapter and Elizabeth Lounsbury, Chair of Polio Canada.

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 Survivors Registry, Health Care Professionals Registry, Education and Information, Support Groups and Conferences. 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, thereby maximizing the impact.

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, because the hospital being funded to run the service decided 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. This is only possible because funding is being provided by pharmaceutical companies producing drugs for stroke recovery. All participants 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.

As an adjunct to this lunchtime meeting, Sheila suggested that we meet up again that evening 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 Roy Essex, a Baptist Minister whose daughter, Sheila, contracted polio during the 1950’s. Sheila was institutionalised due to her dependency on a respirator. Against medical advice, Rev Essex brought his daughter home, learning how to repair her ‘cuirass’ respirator via telephone contact with the manufactures in the USA. Rev Essex went on to volunteer his services with other polio survivors, 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.”

The Experience

Toronto, Ontario, Canada (cont'd)

- **Polio Canada** (cont'd)
- **Key Services/Points:**
 - Discussions between Polio Canada, Polio Australia, Post-Polio Health International and networks in Britain and Europe could advance the formation of “Polio World”
 - Ontario’s only post-polio clinic was closed a few years ago, despite intensive lobbying by Polio Canada and polio survivors, because the hospital being funded to run the service pulled out
 - Joint support group activities with polio and stroke clients is made possible because funding is provided by pharmaceutical companies producing drugs for stroke recovery
 - There is potential for alliances in clinical service provision for a variety of groups ageing with a neurological condition



The Experience

Ottawa, Ontario, Canada

- **Dr Marcia Falconer, Virologist and Researcher**

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 May 2006, Marcia gave us a talk in Melbourne (see write up in Polio Perspectives Winter 2006:

www.polionetworkvic.asn.au/newsletters/items/2006/09/102206-upload-00001.pdf).

What was explained to us during that meeting was written up in an unpublished document Marcia wrote called "Inflammation & PPS", i.e.: "The cause of virtually all PPS symptoms can be explained by one word: inflammation! Front line research in the fields of neurology, immunology, physiology and virology is coming together and the many pieces of the puzzle are being laid upon the table. This is approximately where we are today in our understanding of how inflammation is related to almost all chronic diseases; PPS, MS, ALS, CFS, Parkinson's, irritable bowel syndrome, arteriosclerosis and many, many others."

Further information on Dr Marcia Falconer's theories can be found at:
www.otl.zynet.co.uk/polio/lincolnshire/library/falconer/nonparalytic.html

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" 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. Hopefully, all these ideas will come together in a book (or two) in the not-too-distant future.

The Experience

Ottawa, Ontario, Canada (cont'd)

- **Dr Marcia Falconer, Virologist and Researcher (cont'd)**
- **Key Points:**
 - Inflammation is related to almost all chronic diseases
 - Reducing inflammation can be self-managed and achieved through weight loss, diet, pacing and meditation
 - Clinics of the future should include inflammation specialists to work on stress reduction: physical and emotional and diet
 - There is a place for additional/complementary therapies to be used as an adjunct



The Experience

Ottawa, Ontario, Canada (cont'd)

- **Respiratory Rehabilitation Services at The Ottawa Hospital**

(www.ottawahospital.on.ca/sc/rehabcentre/index-e.asp)

Dr Douglas (Doug) McKim is the Medical Director, Respiratory Rehabilitation Services at The Ottawa Hospital Rehabilitation Centre. Respiratory treatment was not actually something I had considered as part of my original itinerary but when Joan Headley at PHI (see St Louis, Missouri) pointed out this gap, it made sense to include such a service provider.

The percentage of people who experience an increase in 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, as well as scoliosis - has been quoted at around 36% (*Health and Demographic Characteristics of Polio Survivors*, Sandra S. French and G. Sam Sloss, Associate Professors of Sociology at Indiana University Southeast, 1999). 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.

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 do.



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). Two 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, 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: www.irrd.ca/education/presentation.asp?refname=e2r4

The Experience

Ottawa, Ontario, Canada (cont'd)

▪ **Respiratory Rehabilitation Services at The Ottawa Hospital (cont'd)**

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 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 a range of PPS symptoms, respiratory difficulty being one of them.

This same man told me that, unfortunately, there are no polio support groups operating in Ottawa. Although the clinic is excellent in 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 GP and, therefore, not receiving assistance for management of 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.

▪ **Key Services/Points:**

- 36% of people experience an increase in respiratory and swallowing problems as a result of PPS
- Lung Volume Recruitment (LVR) keeps the airway supple
- Most of the tests performed indicated that lung capacity improved with LVR
- If not properly prepared, polio survivors with respiratory problems can experience acute problems following a surgical procedure
- No polio support groups in Ottawa
- No access to PPS specialists in Ottawa

The Experience

Montreal, Quebec, Canada

- **Post Polio Clinic, Montreal Neurological Institute and Hospital**

Dr Daria Trojan is a Physiatrist and the Clinic Co-ordinator of the Post Polio Clinic at the Montreal Neurological Institute and Hospital. After an overview of the clinic by Dr Trojan, 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 Occupational Therapist, Tatiana Ogourtsova. People requiring other treatments are referred out to PPS-aware health professionals in the community. In this team, the OT is responsible for the swallowing and cognitive difficulties that other PPS clinics may refer to a Speech Therapist.



Mary-ann & Dr Daria Trojan in front of
"Nature unveiling herself" sculpture

Clinic Structure

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 (<http://apps.mni.mcgill.ca/mnhpolio.html>):

"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.

The Experience

Montreal, Quebec, Canada (cont'd)

▪ **Post Polio Clinic, Montreal Neurological Institute and Hospital (cont'd)**

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 postppolio 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.

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 PHI (see St Louis, Missouri).

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.

▪ **Key Services/Points:**

- Clinic patients have access to both a physiatrist and neurologist
- OT is responsible for swallowing and cognitive difficulties
- 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
- There is a six month waiting list

The Experience

Montreal, Quebec, Canada (cont'd)

- **Association Polio Quebec** (www.polioquebec.org)

Mr Gilles Besner, the President of Association Polio Quebec 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.

According to their website:

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 included 14 members of the Board 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 me as a gift which will be added to the polio library. The book is available on line through Amazon:

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. 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.



Mary-ann giving presentation at Assoc Polio Quebec's AGM

The audience at Association Polio Quebec's Annual General Meeting was predominantly French speaking, but one of the Board members (a physiotherapist) was kind enough to provide the translation. 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.

- **Key Point:**

- There are many similarities between Australia, Canada and USA regarding the numbers of polio survivors still seeking information and lack of government funding available for resources and services.

Conclusions

- No two Post-Polio Clinics operated with the same combination of therapists. This was very dependent on the qualification and experience of the individual/team who initiated the clinic, i.e. Neurologist, Physiatrist (Physical Rehabilitation Specialist), Psychologist or Respiratory specialist.
- Standard treating specialists consisted of a physiatrist, physiotherapist and occupational therapist. Additional specialists that may either be on site or referred back to the community were: orthotist (if required); nurse clinical, education & research; speech therapist; seating specialist (usually an OT); psychologist; social worker; nutritionist/dietitian; respiratory specialist (if required); orthopedic specialist (if required).
- A model clinic would include access to all of these therapists, as well as an expert in inflammation management (incorporating strategies for relaxation and diet), acupuncture (for pain management), osteopathy (manipulation), and various Complimentary and Alternative Medicine (CAM) therapies.
- All clinics believe that it is important that physicians working with polio survivors know about PPS. The specialists I spoke with stated that they are fully prepared to share their expertise with other medical practitioners – which also goes for our own Polio Services Victoria.
- If no PPS specialist and/or clinic is available, it is vital for the polio survivor to ensure they are as informed as possible about their condition (there is plenty of reading material available through services like the Polio Network and on line) and to educate their own doctors.
- Although I didn't visit all the clinics that work with post-polio patients, these were among the major ones and all were consistently busy with local, national and international patients. It was generally acknowledged that services for polio survivors would be required for at least another 20-30 years.
- There are a number of ageing PPS specialists who do not have successors and whose services are at risk of being absorbed into the general hospital rehabilitation system or ceasing altogether in the not too distant future.
- PPS clinics with a younger, team-oriented approach are likely to continue. However, many are diversifying into working with other neurological conditions which are more likely to attract funding to continue service provision – especially through drug companies. As no medication has been proven particularly effective in the treatment of PPS symptoms, this is not viable in itself.
- With the total USA population recorded at 301,139,947 and a conservative estimate of people identifying themselves as polio survivors being 1,000,000 (PHI statistic), it was surprising to note that polio support groups in the USA have been reduced from well over 300 in the 1980/90's to approximately 150.
- Although polio 'education' and 'outreach' is being done by some individuals/clinics/institutes, this seemed to be confined to schools, community groups (i.e. Rotary), and existing polio support groups, or in the form of information on the website/brochures/posters/books.
- Active community outreach to younger polio survivors who may be unaware of PPS does not appear to be happening in the USA/Canada which, I believe, is reflected in the decline of polio support groups.
- The most effective way of managing PPS symptoms and ensuring polio survivors remain as active and independent as possible is the two pronged approach of self-management techniques coupled with regular specialist clinic assessments and intervention strategies.
- Currently, there very few clinics/institutes/individuals doing PPS research: Post-Polio Health International (Various); John P Murtha Neuroscience and Pain Institute (Various); Dr Marcia Falconer (Inflammation); Respiratory Rehabilitation Services, The Ottawa Hospital Rehabilitation Centre (Lung Volume Recruitment); Dr Daria Trojan (Various). Many of these are quite promising.

Information Dissemination

The information ascertained from these visits will be shared with the Australian polio community via uploads on the Polio Network website, articles the Polio Perspective newsletter, reports sent to the eighteen Victorian support groups, presentations at eight scheduled Victorian 'Polio Awareness Month' sessions, and reports sent and presentations made to the other Australian state Polio Networks.

Recommendations

- Compile a list of medical specialists who expressed an interest in being contacted for polio survivors to give to their own medical specialists for peer-to-peer email consultation.
- Provide this list and relevant documentation provided by clinics to Polio Services Victoria (PSV).
- Compile a kit of self-management strategies and techniques – including CAM therapies – provided by the various clinics to give to polio survivors.
- Promote participation in the monthly “Post-Polio Clinics Directors Network” teleconference among Australian health service providers, including a link from the Polio Network website.
- Continue to provide outreach to polio survivors currently unaware of PPS in the community.
- Record books and DVD’s received and set up library loan system.
- Discuss models of service provision with PSV and other Australian state Post-Polio Networks/Polio Australia.
- Arrange for further discussions with organisations representing other neurological conditions.