



POST - POLIO NETWORK (NSW) INC.

NETWORK NEWS

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President's Corner

Gillian Thomas

Welcome to new members and regular readers. An apology is in order for the delay in publication of this *Network News*. Unfortunately, some health issues conspired against me this time. On the bright side, the delay has enabled the inclusion of some topical events (see pages 2-3 and 20). I hope you find this bumper issue was worth the wait.

On **page 4** you will find full details of our upcoming **Country Conference** in **Ballina** on **Saturday, 15 September 2007** which is being **hosted by the Northern Rivers Support Group**. If you live in the area or are able to travel to the north coast, **please complete and send in a Registration Form by 31 August**. The day will be packed with good information and you are urged to attend if possible.

It is **Membership Renewal** time. You will find enclosed one of two forms, depending on your financial status. If you are currently paid up to 30 June 2007 (your address sheet reads **Renewal Due On: 1/07/07**) you will find a **Membership Renewal Form** enclosed for the period **1 July 2007 to 30 June 2008**. **Could you please confirm, complete, or amend your details as given on the Form, and return it with your subscription to the Treasurer at the Network's Parramatta postal address**. Our Treasurer, Bob Tonazzi, has noted that quite a few members last year appreciated the ability to pay their membership subscription via **internet banking**. Bob has asked that, if you take up this option, please **ensure your name is recorded on the payment and email him at <treasurer@post-polionetwork.org.au> to confirm the payment transaction details**. He says that without this information it may be impossible for us to credit the payment to your membership. Also, if you post in your payment, please be sure to **return the entire Renewal Form** with your subscription – **please don't tear off and return only part of it**.

There are still a few people whose annual subscriptions are overdue, and so their address sheet reads **Renewal Due On: 1/07/06 (or earlier)**. In this case, the **Membership Renewal Form covers more than one year's membership**. We would appreciate prompt payment of the outstanding dues, together with the current dues, to ensure that you continue to receive *Network News*.

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

If you are already financial beyond 30 June 2008 (as shown on your address sheet), you will receive a **Membership Update Form** which gives your current details but does not request payment of a membership subscription. **Please check your details and be sure to return the Form if any amendments are required.**

Member **Elaine Byrne** who was elected to the Management Committee at the Annual General Meeting in November 2006 has regrettably had to resign from her position due to ill health. We wish you well Elaine and hope you are soon on the road to recovery. Member **Rod Macaulay** has been appointed to fill the casual vacancy. Rod will be travelling from the south coast to attend meetings and we thank him for his commitment.

Finally, for some years member **Lynne Ellis** has been **reading Network News on to tape** for members with vision impairment. **Both the Network and those members have been extremely grateful for Lynne's selfless efforts**. Unfortunately, **Lynne is no longer able to take on this important task** due to the late effects of polio and a failing voice. **If there is anyone else out there who is willing and able to provide this important service for members who otherwise cannot read Network News please get in touch with me for further details.**

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Public Health Alert over positive case of polio in Australia

As this issue of *Network News* was about to go to press a national Public Health Alert was issued by Australia's Chief Medical Officer, Professor John Horvath, after Victorian health authorities reported the first case of wild polio in this country since 1986. Media around the country quickly picked up the story, reporting that "A 22-year-old Pakistani student is being treated in isolation at Melbourne's Box Hill Hospital, after he fell ill with polio earlier this month following a visit to Pakistan."

The complete Health Alert read:



Australian Government

Department of Health and Ageing

Professor John Horvath AO
CHIEF MEDICAL OFFICER

13 July 2007

Victorian health authorities have reported a case of polio in a 22 year old male who recently returned by plane to Australia from Pakistan.

The last case of wild type poliovirus infection in Australia occurred in 1986 and the Western Pacific Region, including Australia, was certified as polio free in 2000, so any case of polio is a significant public health concern.

This afternoon a meeting of the Australian Health Protection Committee (AHPC) reviewed the case and agreed on national action to contact trace all passengers who travelled with the infected passenger and to isolate his Australian home contacts.

Passengers on Thai Airlines flight TG999 from Bangkok arriving in Melbourne on 2nd July 2007 should contact the National Public Health Info Line on 1800 004 599 for further information (8.30 am to 10 pm).

The patient, who has recovered from his initial paralysis, will remain in hospital in isolation until he is diagnosed polio free and his household contacts will be asked to remain in home quarantine until it is established that they are not infected.

While the risk to health care workers is very low, all staff who had contact with the patient will also be screened appropriately.

All Australian hospital emergency departments have been alerted to look out for any signs or symptoms of polio.

Passengers who travelled with the case are considered to be at low risk of contracting the disease. The risk of disease transmission to the general community is also considered to be low. However, polio is a highly infectious disease and it is appropriate to take precautionary measures.

Polio has been eradicated in most parts of the world except for a few countries including India, Pakistan, Afghanistan and Nigeria.

Victoria's chief health officer Dr John Carnie said test results on 13 July confirmed that the man, who was admitted on 7 July to Box Hill Hospital, in Melbourne's north-east, had the viral disease. *"Test results tonight from the National Polio virus Reference Laboratory in Melbourne confirmed the presence of the polio virus. ... [The man] will be kept in isolation as a precautionary measure until he returns successive negative test results for polio. ... The doctors at Box Hill Hospital have to be congratulated because this is a disease that has not been seen in Australia for many years and yet they were able to make a clinical diagnosis that has been backed up by laboratory tests,"* Dr Carnie said.

As regular readers of *Network News* will know, while polio has been eradicated in most parts of the world, it still occurs in several countries; as at 10 July, 285 polio cases had been notified in 10 countries during 2007, led by India and Nigeria with 100 and 120 cases respectively (*Source: www.polioeradication.org*). This Victorian case of wild type polio infection highlights the need for Australians not to become complacent about the need for immunisation against polio and other vaccine-preventable diseases.

While Dr Carnie notes that *"In Australia we have a highly immunised society, in fact the coverage rate with vaccine is over ninety per cent"*, in some parts of Australia the immunisation level is much lower. This is an unacceptable invitation for the outbreak of otherwise preventable infectious diseases, especially now that polio has been demonstrated to be only a plane trip away from Australia. The speed of air travel outpaces the incubation period of many diseases – meaning a contagious person can cause an outbreak without so much as a warning sniffle aboard a plane.

By a quirk of fate, ABC Radio National (*Life Matters*) broadcast a series on immunisation choice in the week before this polio infection was announced. In case you didn't hear the series called *The Immunisation Maze*, three sets of first-time parents were trying to work out whether their new-borns should be vaccinated or not. They live on the north coast of NSW, around Byron Bay, which has one of the lowest rates of immunisation in the country – only seventy per cent. And it's an emotive topic there. The couples agreed to seek information for and against vaccination, and to have their investigations recorded for *Life Matters*. The parents spoke with Professor Robert Booy (Co-director of the NCIRS – National Centre for Immunisation Research and Surveillance, at Westmead Hospital, Sydney) and with Meryl Dorey (National President of the Australian Vaccination Network). The couples having weighed up the information they received for and against vaccination shared their decisions in the final episode of the three-part series. One couple *"decided against the polio vaccine because we don't think it's necessary"*. We can only hope that after the much publicised polio case in Victoria they think again.

There is a silver lining in every cloud though. The publicity generated by the polio infection in Victoria generated a lot of media interest not only in polio and polio immunisation but also about the late effects of polio. As a result, Network representatives were kept busy doing radio interviews in places as diverse as the Illawarra, Port Macquarie and Broken Hill. Other state Networks were also spreading the word.



Does Anyone Have An Exercise Bike Looking For a Good Home?

If anyone has an exercise bike stored away and not being used, Alice Smart would be grateful if she could use the bike to help improve her health. Please ring Alice on (02) 9747 4694 if you can help.

Ballina Conference

- Date:** Saturday, 15 September 2007
- Time:** 10:00 am – 4:00 pm
- Registration:** \$15.00 (*includes lunch and morning and afternoon tea*)
- Venue:** Ballina RSL Club
River Street (corner Grant Street)
Ballina NSW 2475
(*approximately 500 metres from the Central Business District of Ballina*)
- Questions?** If you have any queries, please contact
Neil von Schill on (02) 9065 6069 or <support@post-polionetwork.org.au>
or Rosalie Kennedy on (02) 6686 7755

This year's Country Conference for members is being hosted by the **Northern Rivers Support Group**. Through the hard work of the organising committee and Conference Co-ordinator, Rosalie Kennedy, a varied and informative program has been arranged.

Speakers include:

- ❖ **Dr Robert Lodge** – Consulting Physician, Bangalow Consulting Centre
who will speak on polio and assessing the late effects of polio
- ❖ **Kerry Lloyd** – Pharmacist, Lismore
who will speak on pain medication and anti-inflammatory medication
- ❖ **Craig Knox** – Physiotherapist, Lismore Base Hospital
who specialises in assisting with orthopaedic surgery recovery
- ❖ **Richard Grzegorzulke** – Dietician and Radio Personality
who will speak on arthritic nutrition and diets for ageing polio survivors
- ❖ **Val Kwong** – Herbalist
who will examine natural remedies and herbs for physical and mental well being

For those interested, in the evening there will be Live Theatre available courtesy of the Ballina Players with "Cosi" and on Sunday morning there will be Breakfast on the River at Ballina RSL Club.

To assist with accommodation, Network Supporter, **Helen Moore**, has prepared a comprehensive list of motels. If you require this list to assist with your planning please contact Neil and he will email or post it to you.

The cost of the Conference is being subsidised by the Network and so members, carers and friends will pay just \$15.00 per head (*includes lunch and morning and afternoon tea*).

This promises to be a very worthwhile Conference so you are urged to consider attending. If you live in northern New South Wales or have expressed an interest in attending, you will find a **Registration Form** included with this *Network News* – please be sure to **complete and return it with your payment by Friday, 31 August**.

Members from other areas are also more than welcome to attend. You can download a Registration Form from our website at <www.post-polionetwork.org.au/seminar.html> or get in touch with Neil or Rosalie or the Network Office to have a copy sent to you.

Polio Australia - A National Voice For Polio Survivors

One of the aims of holding the Polio Australasia Conference (*reported on in full below*) was to explore with participants whether we should establish a national polio organisation to represent all state Networks and give us a national voice which hitherto has not existed.

All state Networks and New Zealand were represented at the Conference. Much goodwill and resolve were evident in the discussion which was held over a two hour period on the first afternoon of the Conference. The following decisions were all formally moved, seconded and debated using standard meeting procedure.

Firstly it was unanimously agreed that we should establish a national Post-Polio organisation. After spirited and informed debate it was established that the name of the organisation would be "Polio Australia". The New Zealand contingent soundly endorsed the concept but abstained from voting as it was an Australian initiative.

It was agreed that Polio Australia be incorporated and that the word "Inc" be included in the title if legally required. The member organisations of Polio Australia will be Polio Network Victoria, Post Polio Network – Tasmania Inc, Post-Polio Support Group of SA Inc, Post Polio Network of WA Inc, Post Polio Support Queensland and Post-Polio Network (NSW) Inc.

A working party to draft a constitution for Polio Australia and formally incorporate the organisation was established and will comprise at least one representative from each member organisation. This group will work on getting the organisation up and running over the next six months.

To keep the communication lines open between all states as matters progress, an email mailing list of all Network representatives has been set up together with a second email list for the Polio Australia supporters who spoke at and participated in the Conference. An interim website is also being developed and is expected to be launched in the near future.

Polio Australasia Conference - Designing a Future

Since 1991 the Australian and New Zealand Post-Polio Networks have been getting together informally under the name of "Polio Australasia" during the various Polio Conferences held throughout the two countries. Matters of mutual interest have been discussed and communication lines established, even if contact has been rather sporadic.

On 3 and 4 May 2007 for the first time Network representatives met specifically to learn from each other's operations and to debate future directions for the Networks. The Conference was adjudged by all who attended to be a huge success. The primary outcome was the commitment by all Australian Networks to the establishment of Polio Australia – a national voice for polio survivors.

My thanks to Fran Henke from Victoria whose welcome notes formed the basis of this wrap-up of the Conference.

The Conference was hosted by Post-Polio Network (NSW) and attended by polio survivors from all Australian States and New Zealand. The participants' enthusiastic input maintained over two invigorating albeit exhausting days ensured the success of the meeting.

The Conference was opened with a welcome from the NSW Network President, Gillian Thomas, who detailed the history of Polio Australasia. She concluded her introduction with: *“At the last informal meeting of Network representatives following the Victorian Network’s Polio Day in October 2005, I floated the idea of a “Think Tank” where we could all get together in a more structured setting and really debate the issues that are affecting us and our ability to keep the Networks going. I expressed the hope that a National Plan could be developed with input from all stakeholders to ensure that polio survivors receive the information, the services and the support they need into the future. I am very heartened that all Networks have enthusiastically taken up the challenge to formally meet to debate these issues and formulate strategies to, as the Conference title states, “Design a Future”. Who better to do so? In conclusion, all the Networks are reaching a critical stage in their evolution. We are all getting older and more affected by our disabilities. We must therefore make sure we seize the opportunity presented by this Conference. Thank you all again for making the effort to attend and I am sure we are all looking forward to great outcomes for our members.”*

The Conference was MC’d exceptionally well throughout by Neil von Schill, NSW Network Secretary and Support Group Co-ordinator.

The first session was spent providing an overview of the operations of the various States and New Zealand. Ray Wilson brought a team of five from New Zealand, telling about their approaches to government with the usual response of *“we will look into your needs”* followed by nothing further. New Zealand has regionalised its health service to their concern, resulting in the loss of a useful Centre of Excellence. The Post-Polio Support Society New Zealand has 700 members in 22 support groups.

Mary-ann Liethof, Polio Community Officer with ParaQuad Victoria reported that Polio Network Victoria receives (via ParaQuad) state government funding from the Department of Human Services to provide information and support to people who have had polio, their families and carers, and to oversee 20 support groups. Mary-ann has 1,600 polio survivors on her data base and this number is growing. For instance, after good publicity on a Ballarat trip she attracted 50 new people.

Arthur Dobson, Secretary of Post Polio Network –Tasmania and Editor of *Tas Polio News*, is very active. The Network has a good relationship with two of the three Divisions of General Practice in Tasmania. Arthur represents the Network on the peak disability body *Tasmanians With Disabilities* and is a member of the *State Council of Tasmanians With Disabilities*. Membership of the Tasmanian Network remains at around 120 with inquiries bringing just enough new members to replace those who pass away or otherwise leave.

Trevor Jessop from the Post-Polio Support Group of South Australia spoke of the various post-polio groups within his state. The Post-Polio Support Group is linked with Disability Services which provides \$40,000 per year for physiotherapy services. The Group has 245 members.

Western Australia is very active with Tessa Jupp, a registered nurse, running their organisation, Post Polio Network of WA. Tessa has 2,000 on her newsletter list – two thirds in the metropolitan area and the remainder in the huge expanse of rural Western Australia. WA runs their own clinic with an annual turnover of \$120,000 through the sale of supplements and with energetic fund raising, raffles and appeals. They have surveyed their members, run a website, and produce kits for health professionals. Many people avoid meetings but go to the Christmas party.

Queensland’s Jo Toia co-ordinates member networks at the Spinal Injury Association. Polio survivors and people with spinal cord injury participate in these networks. Following a recent visit to Victoria, she is also travelling around the country finding new people to join and/or start up new support groups.

To wrap up the state overviews, Gillian Thomas reported that the Post-Polio Network (NSW) has around 1,000 financial members – 90% are over the age of 55, while 40% are over 70. The Network receives no government funding and its operations are funded by membership fees and donations. NSW has 11 metropolitan Support Groups and 15 in rural areas, including one in the ACT, plus 5 Regional Representatives in areas where there are no Support Groups. Some Groups meet face to face while others provide telephone support. The Network also has a comprehensive website, provides information kits about the late effects of polio, publishes quarterly Newsletters and Information Bulletins, and has produced a range of resources for members.

After morning tea, in her session on *Overview of PPN Research Outcomes*, Merle Thompson gave preliminary results from her questionnaire which was directed to polio survivors and a control group. Questions covered how much people's condition has changed in recent years; dependence on family as carers; how will couples maintain their independence, given that spouses are also ageing; and medical problems such as sleep, falls, and flu-like symptoms. Questionnaires were sent to 863 members with an excellent 57% response rate – 488 forms were validly filled in which were more than enough for analysis. Years of infection ranged from 1916 to 1980 with peaks in 1937-38, 1945-46 and the early 1950s. In brief, they showed that 74% of respondents had muscle and joint pain; 92% complained of weakness; 89% suffered from fatigue; 65% felt the cold; 65% had sleep disorders; 38% had swallowing problems; voice issues also were common, for example a failing voice; many reported memory problems, particularly evident in "losing words". The questionnaire also asked about aids – sticks, crutches, chairs, orthoses. It asked how people got around: 101 respondents couldn't walk around their homes; only 42% could easily be a passenger in a car. This is just a brief coverage of two years of Merle's work.

After lunch on day one the subject of a national voice was raised and Glen Boyd, Regional Development Manager, Northcott Disability Services, was a terrific speaker. He talked about the devolution of responsibility for disability services from Federal to State Governments and the rise of big charities to corner the market for funding in the 1980s. He spoke about how to target board members of corporations for money. Questioning on his inspiring talk was lively. He suggested talking about "unmet needs" when approaching government and told how to make the group's needs fit under the area of funding by looking at where funding goes and tailoring our tender to those areas.

Dr Stephen de Graaff, Rehabilitation Specialist, Cedar Court, Melbourne, said that we need to target the disability sector. There wasn't the funding for the curative area so it was wiser to go down the disability path (where there isn't much funding either). He said the next 20 years will be crucial for polio survivors needing proper services. Denial is big – only when the problem becomes catastrophic will we go for help and that often is too late. He said we have to get people to recognise the problems before they became catastrophic. Mary-ann Liethof commented that there is a free service with ParaQuad for access to a psychologist but, of those using it, only 1% are polio survivors.

For the rest of the afternoon we debated forming a national organisation. The debate was vigorous but convivial and by the end of the session the Australian states had not only agreed to form a national organisation, but had agreed that it should be called "Polio Australia". The role of Polio Australia was not discussed or debated in depth at this point.

Participants had dinner together at the Parramatta Leagues Club which was very pleasant with us all moving around tables, getting to know each other better.

First up the next day was the task of identifying services required with Dr de Graaff welcomed as the guru of polio physicians. He detailed the symptoms we suffer in order to relate to the services we need. He understood our psychology, talking about denial, our toughness and desire to overcome, while repeating the need to diagnose properly to

eliminate other illnesses. He said one of his patients actually had MS while another had a tumour so we were reminded not to put everything down to post-polio. Polio survivors tend perversely to do things at the expense of our health. As we get old our bodies naturally start to wear out. We have to deal with the scepticism of doctors and we have to teach doctors to go beyond that, he said. We need educated physiotherapists too. A good physiotherapist treats the whole person. He was very big on psychological and emotional problems saying if we can get people to face the challenges then the challenges can be better managed. A psychologist should therefore always be part of the treatment team. He spoke about taking analgesics such as panadol-osteo (not easy to get in rural areas) before going to bed because fatigue was a major factor. He went through a list of services such as occupational therapy and orthotics, and talked about conditions that need treatment such as swallowing difficulties, respiratory issues, sleep-disordered breathing, thermo-regulation problems, and how heat aggravates fatigue and cold aggravates pain. He said when he assesses a new patient he asks for the partner to be there because they are more honest. He spoke about the need for us to be treated with respect and dignity finishing "*I know when I meet a polio survivor they say 'can you help me to help myself', others say 'I want you to help me'*". People don't use their physiotherapist unless they're married to them was another good line. He spoke about exercise and the need for a non-fatiguing program. He spoke a lot about sleep and noted that if we wake up tired we could have sleep apnoea and a sleep expert should be consulted. Energy conservation: decide what you want to do and use a chair for what you have to do. Otherwise everything becomes a chore and you don't do anything. Stop before you become exhausted.

"Jega" Jegasothy, Senior Physiotherapist, Late Effects of Disability Clinic, Royal Perth Hospital, spoke next about the main problems being over-use, weight gain, and lack of research into symptoms across Australia. Even in a chair we can burn off weight. Jega questions "Why should a disability put us in a nursing home?". Health professionals need training in dealing with us; collaboration without the burden of red tape.

Jane Henderson, Service Coordinator and Physiotherapist, Polio Services Victoria, spoke about the services at St Vincent's and the lack of state government support despite a huge increase in clients. The figures of survivors trying to access clinical assessment services at Polio Services Victoria have quadrupled since it commenced in 1997, and the average age has dropped from 69 years to 48 years as young migrants arrive from countries where polio is still being contracted.

We then broke up into workshop groups to talk about identifying services required based on these presentations. Lunch was again a very pleasant affair in the courtyard soaking up the warmth of a clear autumn day.

After lunch John Tierney, former Senator and now a Director of Government Relations Australia, spoke about his work with government relations and how we might best bring our issues to government decision makers. As a polio survivor, he noted that he is in "the same life boat" as us.

We spent the final session really enthused by his talk as evidenced by the increasing volume in the room! The workshops explored how Polio Australia could be set up and what its role could be. Ideas for the latter included: educating health professionals and the community about polio and its late effects; garnering support from all levels of government for services for the increasing number of polio survivors now experiencing the late effects of polio; supporting continuing vaccination against polio in Australia and overseas; and encouraging and supporting research into the late effects of polio.

In closing the proceedings, Gillian remarked that the Conference had fulfilled all her visions for it and more. The next steps would be the development of a Constitution for Polio Australia followed by its formal establishment.

Walking and Bracing Support Systems

This easy-to-understand explanation of the mechanics of walking and how orthotic support systems can help has been assembled by the Post-Polio Network (NSW) from a collection of excellent documents published by DynamicBracingSolutions Inc on their website <www.dynamicbracingsolutions.net>. DynamicBracingSolutions is based in San Diego, California, USA, and is currently developing a national network of practitioners dedicated to providing their patients with unsurpassed bracing solutions. The company aims to provide solutions to deficiencies in locomotion resulting from neuromuscular disorders on an individual basis. The paper is published here with the kind permission of DynamicBracingSolutions Inc. Requests to reprint the paper should be sent to Marmaduke Loke, CPO at <Solutions@DynamicBracingSolutions.net>.

The paper provides background to the presentation given to members on 16 June by Mark Raabe, Orthotist/Prosthetist, OrthoSynergy Pty Ltd, entitled "Overview of Orthotic Stance Phase Control Systems". You can learn about Mark's presentation on pages 17 and 18.

Walking is moving by taking steps at a pace slower than running. While energy is definitely consumed during this activity, it is minimized by the symmetrical advancement of body parts. This creates an efficient rhythm allowing energy to be carried over from one step sequence to the next when walking on a fairly level surface.

Discounting getting up, stopping, or turning, a lot of our normal walking activity is usually done in a fairly straight line. This means that from one step sequence to the next, there is some energy carried over. This minimizes the amount of energy that we use. Thus, all of our body segments (arms, trunk, legs, head) displace minimally and add to a primary, or net, force. The velocity or speed of our body during walking is sustained, if not constant. This is probably as close as we will ever get to Isaac Newton's concept of momentum as stated in the First Law of Motion whereby a body in motion tends to remain in motion.

It is a normal response for humans to seek out external support systems when the body becomes fatigued. People unconsciously seek a safe structure on which to rest for efficiency when they are placed in demanding or stressful situations. Observing people at gatherings, you may notice some resting against a wall or leaning back on a chair. Others may be leaning on counters or walls without realizing they are doing it. This is especially true during activities involving prolonged standing. When such activities result in discomfort, balance problems or fatigue, the sensory input will cause the individual to react. In these instances, people without physical limitations use support systems such as handrails, armrests and backrests. Support systems are not used exclusively by physically challenged individuals.

When someone has physical limitations and the ability to stand and walk is compromised, the need for support systems becomes more important. Support systems in the form of custom bracing vary according to the design and choice of materials. The objective of such a support system is to provide for stability and mobility simultaneously. The goal is to support involved body parts without undue restriction and allow for efficient ambulation.

Support systems in all orthotic applications need to be placed where they are needed most. It is necessary to differentiate these systems according to each person's needs. Custom braces should not be the same for everyone. The location of support systems combined with high tech materials is critical in achieving efficient ambulation and maximizing potential. Traditional braces for ankle deficiencies relied upon support behind the calf and were made of metal and leather or plastic. In many cases where the knee was involved a long leg brace was used keeping the knee straight during ambulation. As new materials

became available, metal and leather were replaced with plastics; unfortunately, the “old theory” remained and designs did not change.

The old theory regarding support systems has become the traditional approach when treating people with physical limitations that affect ambulation. It is necessary to reconsider the biomechanical needs of each individual and design the most appropriate orthosis for that person. New materials alone do not change the functional characteristics of a support system. It is the combination of design and materials based upon specific biomechanical requirements that are essential to restoring balance, security, and the ultimate goal of functional efficiency in ambulation.

Support systems are intended to help the individual. They can often impose limitations on balance, security and efficiency! This is important to understand since the old theories have become entrenched in our thinking as professionals and clients. A support system that is applied below the knee has a profound effect on the knee and hip musculature above as well as the entire body! It is impossible to create a support system below the knee and not affect the rest of the body. Since this is a given, we must address the body as a whole in our choice of design and material when creating support systems. An orthosis should enhance efficiency. It should not add to the effort required to ambulate nor should it increase energy expenditure. The term “support system” is more descriptive than orthosis or brace as it implies a functional process and the use of critical thinking.

In order to achieve an efficient gait that is balanced and secure, the knee and hip joints need to be free to move through swing phase yet allow for stability in stance. As stated earlier, the location of support in a standard AFO (ankle-foot-orthosis or short leg brace) is behind the calf. In order to feel this support, it is necessary for the individual to lean back into the plastic shell or calf band. An efficient gait is fluid and motion is always forward. Many people wearing such conventional devices are leaning and often use muscle power to maintain the leg back in the brace. The need to push back while moving forward is counter-productive. Compensations then need to be made because of the orthosis; consequently, balance and efficiency are adversely affected. Complete extension of the knee or hyperextension (recurvatum) is not part of a normal gait cycle. The knee maintains varying degrees of flexion throughout. These compensations cause increased energy expenditure, fatigue, balance problems and insecurity. The overall inefficiency is being caused by the brace! The mechanics are all wrong!

The use of free dorsiflexion in a support system would seem to be consistent with the concept of moving forward throughout the gait cycle. This design has gained popularity without addressing security issues or efficiency. Video documentation has shown the shortcomings of this design. The support system behind the knee in combination with free dorsiflexion creates a “drop off” at the knee, which prevents full weight bearing on the affected side during stance; in other words, it is an ineffective approach that increases difficulties with balance, security and efficiency.

The issue of security takes precedence over balance and efficiency. Humans need to be safe and feel secure. Compensations for security reasons are made at the expense of balance and efficiency. Habits develop that become normal to the individual over time. This leads to a further deterioration of function. It is a vicious cycle that needs to be broken. Old movement patterns have to be replaced by new or more natural patterns in order to reach one’s potential. An appropriate support system will allow the body to assume more normal patterns required for balance, security and efficient gait; however, retraining is necessary to overcome the compensations established over time.

Security issues are concerns about safety. They involve activities or movements that elicit fear. We don’t want to get hurt. In the case of physically challenged individuals, the fear is usually of falling. Security issues are based on actual events and justifiable concerns. An

example of a security issue for anyone is walking on ice. One discovers quickly that they must alter their walking strategy. It may be based on a previous experience or the mere fact of losing control without actually falling. One soon learns to alter their walking strategies. Most people will crouch down a little and spread their feet out. This lowers the center of gravity and increases the foundation. The concentration required for movement is intense and becomes the primary focus of attention. Shorter steps or even shuffling the feet without lifting them is safer. Arms are spread out to help with balance. All these compensations are made to reduce the security risk. If these strategies don't work, it may be necessary to get down on all fours and crawl to safety.

It is human nature to make compensations for security reasons. Security issues in post-polio can become a routine part of daily life. This may happen gradually over time with aging or early effects of post-polio syndrome or are a way of life since the initial onset from the polio virus. Each falling episode has a cumulative effect. Ultimately ambulation becomes a conscious effort. Normal ambulation is an unconscious activity. Security issues can make ambulation a conscious activity. This creates compensations, balance problems and a lack of efficiency. Until the security issues have been solved, compensations will be made. In the case of a typical individual on ice, the security issues are eliminated upon reaching dry ground. For the individual with post-polio, security issues become ingrained in the subconscious mind; in other words, the compensations become normal in spite of the lack of efficiency. Understanding that they exist, recognizing and understanding their purpose and providing a solution can return security and efficiency to near normal levels.

Security issues causing compensations in post-polio are learned activities. They ultimately become habits. Each person demonstrates unique characteristics and degree of severity. The most common examples of security issues in gait are decreased standing and walking balance, tripping over the feet, ankles rolling over and, for some, knees buckling.

Difficulty with balance is one of the most common security issues in post-polio. This is caused by a combination of weak or no muscle power and progressive deformities. The foot and ankle complex as well as the knee are the most common structures affected by progressive deformities. Balance is normally maintained by a complex array of neurosensors, muscles, and proper structural alignment. This is called proprioception. Proprioception can be defined as the awareness of the body in space or the awareness of the position of a body part without visual cues. As the body leans too far, sensors send messages to activate muscles to oppose that movement and return to the original upright position. In post-polio, the sensors are usually working that provide proprioception but the muscles may not be working properly. Instead of small activation of a few muscles to maintain standing in one place, the individual with post-polio often recruits other muscle groups to compensate to right themselves. Rather than subtle isolated muscle contractions to maintain balance, the recruited muscles are usually at a mechanical disadvantage and must activate longer and stronger to accomplish a similar task. This is often at the price of efficiency and over taxing the system.

There are a great many deformities and functional deficits, but there are a limited number of major compensations with many subtle compensatory movements that are possible. There are only so many ways that the body can make gross movement compensations in order to balance and walk in an upright position. All of them require excessive energy use. Some of them may result in secondary deformities if not addressed. All or any of them identify the way you walk as abnormal.

Normal ambulation involves the coordinated effort of the entire body. This involves the head, trunk and arms as well as the legs. Ambulation has been described as a *series of falls* following a *period of recovery*. This is a learned activity and requires confidence. It is

efficient and appears to be one continuous motion. In actuality, it is a complex series of movement patterns. Under routine circumstances, ambulation is automatic and does not require conscious thought.

In the presence of special conditions, it may be necessary to actively think about the act of walking. A person on the high wire uses compensations involving the whole body in order to maintain balance and security. The arms may be extended out to the side as a counterbalance to the decreased base of support. Walking on ice is another activity that requires compensations to ensure balance and security. The toddler learning to walk has a very wide base of support and uses gross body movements or compensations to avoid falling down. There is a learning curve that must be mastered before ambulation can become an unconscious activity. These counterbalances and gross body movements ultimately give way to effortless and efficient gait as the individual matures. Compensations are normal responses to activities that affect balance and security.

Individuals with physical limitations must use compensations on a routine basis. These compensations are evident in movement patterns that can identify an individual from a distance. Muscle weakness with associated muscle imbalance, joint deformities and limited range of motion or surgical fusions are common causes resulting in a loss of balance. Compensations become an unconscious habit over time. The repetitive nature of these movement patterns decreases efficiency and places a tremendous burden on the body.

Compensations vary in complexity according to the degree of deficiency and loss of balance. They range from a single arm movement in one plane to many movement patterns involving multiple planes of motion. Instead of all the body parts working in harmony, they move contrary to the intended direction. The symmetry of gait is lost. Efficient gait requires the body to continuously move forward with minimal deviation. Compensations involving the trunk, pelvis, arms and legs cause gait deviations. The deviation of these body segments can be forward or backward, up or down, side to side, rotational or any combination thereof. The analysis of the complexities of compensations, their underlying causes and how to eliminate them is a demanding task.

Among the more common compensations are the following:

- Truncal deviations in which the trunk shifts to one side or to the other or moves forwards or backwards. This balancing strategy is horizontal in nature as about 70% of the body's weight shifts.
- Excessive hip flexion in which the hip muscles lift the entire leg against gravity, usually to compensate for a drop foot or an ankle contracture. This functional strategy is vertical in nature as about 15% of the body's weight is lifted against gravity.
- Circumduction or a swinging of a leg to one side to advance the leg and clear the ground. This functional strategy is also vertical in nature, lifting about 15% of the body's weight. Frequently, however, it is combined with the following strategy.
- Circumduction of a leg accompanied by a shifting of the trunk to the other side. This is a classic seesaw application as the shifting trunk makes possible for the outward swinging of the leg on the other side when the hip muscles are weak.
- Hip hiking or lifting the pelvis on one side. This is a vertical strategy frequently used to assist the leg in clearing the ground.
- Vaulting or raising almost all of one's body weight vertically against gravity. This is an exhausting strategy frequently used to also help in clearing the ground on the other side. It is also sometimes used to regulate timing. By raising the body's weight

during vaulting, the velocity or speed of the body decreases. This is sometimes necessary to allow the other leg to catch up.

It is important to understand these compensations from the point of view of the client as well as the clinician. Humans are very adaptable. When compensations become habit, security is achieved at the expense of efficiency. The patterns of movement utilized in this effort become as unconscious as “normal ambulation”. All compensations detract from the net force of moving the body forward. Inertia (momentum) is lost and rhythm and symmetry is disrupted. It is like driving while alternately hitting the gas pedal and the brakes. Smooth acceleration to a “cruising speed” is replaced by a series of starts and stops. In ambulation, the most energy is expended in acceleration and deceleration. The pre-set cadence that each individual is endowed with is altered which decreases the efficiency of the gait cycle even more.

Approximately 70% of the body mass is concentrated in the upper body consisting of the head and trunk. The remaining 30% is distributed between the lower extremities. In single leg support, 15% of the body mass is supporting the remaining 85%! In normal ambulation, this can only be efficient through balance and inertia as the body moves forward. Compensations that deviate from this forward progression of the body increase effort and energy expenditure to extraordinary levels. As the trunk leans to the side and back while the pelvis rotates in the process, 70% of the body mass is going in the wrong direction! The supporting limb may also be supporting the body mass for longer periods of time as asymmetry increases. In cases of one-sided involvement, it is no wonder that the “good leg” presents more problems in terms of pain and orthopedic problems. If both legs are involved, the effort will ultimately lead to a sedentary lifestyle.

With the proper assessment and appropriate orthotic support system, balance can be re-established and eliminate the need for compensations. The elimination of the habit resulting from these compensations will require conscious effort on the part of the individual to benefit from the orthosis. Fixed deformities, contractures or weakness of the hip musculature will require continued compensations but these can be minimized.

Should an orthotic brace or a prosthesis address the compensations as well as the deformities? Yes. If the design and training do not incorporate features for the compensations, it will not be possible to balance properly while walking nor will it be possible to sustain the velocity or the rate at which you are walking. Also it will not be possible to attain a normal way of walking.

Tripping or the loss of balance heightens the awareness of security issues and the fear of falling. The most common compensation is to lift the whole leg high enough to clear the foot that is dropping. As weakness progresses, the leg must be lifted higher. This compensation is called high steppage gait. One must lift 15% of one's body weight straight up against gravity on each step. This involves increased energy expenditure and creates balance problems.

The ankle rolling over also affects balance and the fear of falling to one's side unexpectedly. This is caused by deformities from an imbalance of muscles. Certain nerves are affected more than others, thus affecting the precious balance of muscle strength.

People with post-polio tend to have structural deviations caused by muscle imbalance and/or lack of proper support under load bearing applications. Some polio survivors have a discrepancy that causes excessively high arches called pes cavus. As the deformity increases, the ankle is very susceptible to rolling over to the outside. Falls, ankle sprains, and even fractures are all quite possible and common. The compensations are spreading the feet, slowing down, shorter steps, quicker steps and no longer shifting one's body

weight over the feet. Ultimately, balance becomes impossible.

The buckling of the knees is very common, the resulting security issue dramatically increases the chances of falling. To prevent the likelihood of knees buckling, one will start snapping their knees backwards on each step. This creates hyperextension at the knee (also called recurvatum). This repetitive compensation in time stretches the structures on the back of the knees. The structures involve ligaments, tendons, joint capsules, nerves and blood vessels. The recurvatum is classified as mild, moderate and severe and will progress if not prevented. Pain can also be associated with recurvatum. To be secure, one rapidly moves 15% of their body weight 180 degrees away from the intended forward direction. A secondary compensation often associated with recurvatum is the forward movement of the upper body over the weight bearing leg during stance. Before a step can be taken on the other side, the trunk must move backward and to the opposite side. Since the trunk comprises 70% of the body weight, this constant and repetitive movement increases effort and energy expenditure tremendously! The body is literally moving in opposite directions at the same time! This is extremely inefficient.

In order to be effective, bracing solutions must recognize and address all security issues. This includes structural and functional deficits in addition to the compensations and their causes that are unique to the individual with post-polio. Deviations and habits caused by security issues must be solved in order to achieve balance and efficiency.

Remodeling tight structures will improve security, balance and efficiency as well as improve weight distribution on one's feet. As anatomical positioning improves, security and balance improve. This allows for the restoration of proper movement patterns that ultimately leads to optimal efficiency and a return of a normal gait.

Human locomotion is not a two dimensional activity. We describe three planes of motion (triplanar) necessary for normal ambulation. In actuality, the body moves in an infinite and constantly changing number of planes. For educational purposes we will discuss three: forward and backward; side-to-side; rotation. Combinations of these planes of motion make up the movement patterns for all of our activities. The relationship and alignment of our body segments continuously change over a period of microseconds for efficient ambulation and other activities. Education is an important part of the treatment plan. Understanding the forces applied by an appropriate force system and how the body interacts will allow for the gradual replacement of old habits with better mechanics and efficiency.

Walking should result in as little energy consumption as the neuromuscular condition permits in an individual. Orthotic brace and prosthetic design and training should minimize any increase in the amount of energy consumed. Good design should have as a goal the conserving of energy and, where possible, the storing and release of energy to prevent excessive and early fatigue. This is not only desirable for polio survivors but for any patient displaying deformities or mechanical deviations.

Ignoring certain aspects of walking such as starting, stopping, or changing direction or speed, walking is cyclical. The most commonly accepted basic cycle is from the moment one heel strikes the ground until the same heel strikes the ground again. The amount of time that this cycle takes is easily measured clinically with computer assistance. This allows for a comparison of what the left leg is doing compared to the right leg.

The gait cycle has a stance and a swing phase for each limb. There is a normal time relationship of 60% stance phase and 40% swing phase that each limb cycles through with each step. This 60:40 ratio is affected by gait deviations. To achieve a sustainable velocity is critical for a normal gait appearance. Thus, the stance-to-swing ratios serve as a good clinical tool to measure success.

Orthoses are now judged similar to prosthetic knee joints. How well they control the lower limb in swing phase and stance phase of the gait cycle determine their success. The new designs have made the biggest impact on stance phase control capabilities. The stance phase of walking is where all the potential destructive forces of load bearing takes place. As weight is borne on the load bearing column, the limb and/or orthosis must generate enough force to counteract the forces tending to buckle the limb and to enable a fluid progression. These moments are normally counteracted by muscle action. In the absence of normal muscle function, the orthoses must provide the needed functions or disabilities may result in an aberration from normal gait. The combination of triplanar and balance control, better floor reaction designs, and energy response capability all enhance the stance phase control of the new designs.

The swing phase aspect of the gait cycle is the easiest to orthotically control. It requires minimal effort to support the extremity in the swing phase of the gait cycle. The new designs are enhancing the swing phase, as well as capitalizing on the advent of energy response designs. The energy released by the orthosis at terminal stance propels the leg up and forward. The velocity of the swinging limb is increased which helps the body to move forward and re-establish the normal swing-to-stance phase ratios. This allows the energy from one step to be transferred to the next step, thus taking advantage of inertia and momentum.

Is normal walking possible with an orthosis or a prosthesis? In absolute terms, probably not. In relative terms, a normal walking appearance is often realizable.

Being fitted with a lower limb orthosis (brace) or prosthesis (artificial limb) does not at all guarantee that you will walk normally. It should, however, improve your walking. The design, fit, and alignment of the device as well as the subsequent training all contribute to the static balancing necessary to potentially achieve a normal gait.

The intended result of an orthosis or prosthesis is to prevent or correct deformity, transfer weight, improve balance, and increase the speed of walking.

Having said this, orthotic design and technology has not kept pace with the benefits realized in prosthetics. Carbon graphite foot/ankle systems enable amputees to walk with a normal gait and even to run. These systems incorporate the use of energy storing principles. Loading of the prosthetic foot stores energy due to the materials used and the forces applied during ambulation. This replaces the action of missing muscles. As more pressure is placed on the component, it deflects or yields to the weight of the force applied. In this way movement is allowed while stability is maintained. The precise combination of energy storing and energy dissipation simulates normal gait characteristics.

The majority of people with AFO's have learned to walk with conventional designs. Some did well while others realized little benefit. Regardless of past experience, the potential exists for improvement. The knowledge and skills for sophisticated lower limb orthotic support systems utilizing new theories, designs, materials and movement strategies have been developed. Outcomes once thought unattainable are now being realized. More secure and efficient ambulation is possible.

The orthotist of the future will need to employ more sophisticated elements to stay abreast of the advancements. People in need of bracing solutions will greatly benefit. Outcomes now thought life changing, will become the standard. The future client will have fewer falls, better balance and more security. A more natural gait appearance is the result with improved velocity, more endurance, and enhanced functional gains. All these elements are the quintessential result of improving efficiency of human locomotion.

In giving his permission for publication of the preceding article, Marmaduke Loke gave some further insight into his work which I thought should be shared with readers. He wrote:

I am most interested in this subject of Stance Phase Control orthoses. I have been practicing true Stance Phase Control in all my lower limb orthoses (braces) since the early 1990s, long before the latest fad of new Stance Phase knee joints became available. They may or may not provide dependable stance phase control. Most of the SPC knee joints of today are first generation and hopefully more improvements will be made in the next generations.

The great news is people are now starting to think and consider the benefits of stance phase in bracing. Conventional bracing systems that are available world wide are primarily single plane (sagittal) verses triplanar control devices. They are primarily swing phase control braces. The swing phase of gait, when the foot is in the air, is by far the easiest to accomplish. Most Stance Phase Control knee joints are attached to conventional or modified conventional designs.

True Stance Phase Control is much more than preventing the knee from buckling. Stance Phase control must include how the whole limb and foot is controlled from the ground up and how they improve pathomechanics to a more natural biomechanics. Stance phase requires control and realignment of each bony segment (26 in the foot) of the lower limb to be supported to optimize balance and security under full load bearing on an affected limb. It must apply corrective forces for each bony structural deviation in each dimension, yet be designed for restoring more natural and efficient biomechanics. Another term for this is Triplanar Control. The design must take in consideration each millisecond of the gait cycle in each dimension, not just one aspect of the gait cycle. There are many aspects of the gait cycle.

I agree true definitions should be made for better clarification. Many terms are utilized too broadly and too comprehensively. The new theories, technologies, and methodologies developed by DynamicBracingSolutions are based on very complex principles.

We are outcome driven and independent research is validating our outcomes. One such study has documented a reversal of disuse atrophy in several polio survivors by two physicians and two Physical Therapists that are polio specialists.



Queen's Birthday Honours - 11 June 2007

We were very pleased to see that Paul Galy, David Windsor Shoemaker, Bondi NSW, was awarded a *Medal of the Order of Australia* in the recent Queen's Birthday Honours. His citation read: "For service to the community as a medical grade footwear practitioner and manufacturer." The many Network members who have had their footwear made by Paul over the years will attest that this honour was richly deserved. Well done, Paul!



Can You Help to Promote the Network ?

We are most grateful to everyone who has been able to distribute our pamphlets widely throughout their local communities. If any member can help to get the message out about the late effects of polio and the Network by putting more pamphlets on display in, for example, pharmacies, doctors' surgeries or waiting rooms, clinics, shopping centre notice boards, libraries and community health centres, please contact the Office during business hours, or Alice after hours by phone (02) 9747 4694 or email <ea@post-polionetwork.org.au>, and some will be posted out to you.

Overview of Orthotic Stance Phase Control Systems

In June, a Network Seminar was held for the first time in the Sutherland area. This enabled members in the area to attend a Seminar close to home, and those further afield to experience a new venue. A good number braved the wild rainy weather to hear guest speaker Mark Raabe, Orthotist/Prosthetist, OrthoSynergy Pty Ltd, give an interesting presentation on the range of orthotic stance phase control systems now available in Australia. As noted in the article on pages 9-16, such systems provide a more normal gait pattern and reduce the effort required for people with lower limb weakness and paralysis to walk.

This was Mark's second presentation to Network members – he last spoke to us in March 2003 on the topic *Advances in Orthotic Management* and we were looking forward to hearing an update. (Mark's previous presentation was reported on in *Network News*, Issue 58, May 2003.)

Mark Raabe graduated in 1984 from the Lincoln Institute of Health Sciences, Melbourne with a Dip App Sci P&O. His employment history reveals over twenty years experience in all aspects of prosthetic and orthotic prescription and manufacture:

1985 – 1987 : REIS Orthopaedics (Sydney) – Prosthetics & Orthotics

1987 – 1988 : RALAC Melbourne – Prosthetics

1988 – 1989 : Orthopaedic Techniques (Melbourne) – Prosthetics

1989 – 2000 : Otto Bock (Sydney) – Technical coordinator – National Sales Manager

2000 – present : OrthoSynergy (Sydney) – own Orthotic Company

Mark has been consulted by a number of Network members and is well placed to appreciate our individual and unique polio-related issues. His presentation covered the following Orthotic Stance Phase Control systems:

- Microprocessor "E" Knee
- Horton Stance Control Knee Joint
- UTX Free Walk
- FullStride
- Swing Phase Lock Knee
- Load response Knee
- Electronic lock knee
- Ultraflex knee
- Unilateral upright systems
- Blue Rocker

Mark explained that historically there have been two orthotic knee joint options: locked and free motion. A new generation of orthotic knee joints was introduced in 2002. These joints provide stance phase control (knee stability) allowing knee flexion during swing. However, these new devices do not suit everyone and care must be taken when prescribing them to ensure a good outcome for the wearer.

Stance phase control knee joints can be classified into three styles: mechanical, spatial and electro-mechanical.

Mechanical Joints

- ❖ The **Load Response Knee** and the **G-Knee** are known as hybrid types. The Load Response model provides resisted knee flexion up to a maximum of 18 degrees, together with cushioning at initial impact. The G-Knee is an extension assist joint utilising a gas strut. Differing strength gas struts are available. It is possible to lock the knee joint. Mark stressed that the G-Knee does not resist knee flexion and this must be taken into account when assessing whether it is suitable for a particular person.
- ❖ If a client has poor hip extensors which prevent him/her from stabilising the knee joint then the mechanical hybrid knee joints are not suitable. Quadriceps weakness will not preclude the prescription of one of these joints, however, provided that the hip extensors are able to stabilise the knee.
- ❖ The **UTX® Free Walk** is an example of a mechanical stance phase control (SPC) joint. The tubular stainless steel design weighs approximately 900 grams. There are two models: Swing and Stabil. With the Swing model, the knee joint is unlocked by ankle dorsiflexion. These joints have a safe design because a series of events is required to unlock the joint. The Stabil model locks and unlocks by control of the user.
- ❖ The **FULLSTRIDE™** joint is another example of a mechanical SPC joint. It features a cable actuated knee joint which uses existing componentry. It is a low cost/risk design because it allows clinicians to experiment with Stance Phase Control.
- ❖ The last example of a mechanical SPC joint that Mark demonstrated was a **HORTON SCOKJ™**. This is a multifunction, weight-activated joint (dual mould orthosis design). The joint is not widely used in Australia.

Further information on the range of Horton stance phase control knee systems can be found online at <www.stancecontrol.com>.

Spatial Joint

- ❖ Mark then demonstrated the **BASKO SPL™** pendulum activated knee joint. Here, a medial joint provides variable swing phase control. This model is a multifunction joint via satellite control – the SPL is provided with a control element that is connected to the hinge by a cable; apart from mounting on the brace, this satellite can also be slid over the waistband with the advantage that for knee joint control one does not have to reach for the knee.

Electro-Mechanical Joint

- ❖ The final stance phase control knee joint that Mark showed us was the **E-KNEE™**. This is an electro-mechanical model which is footplate activated. The electro-magnet pulls gear faces apart – when the power is on, the knee is free; when the power off, the joint locks (the leg can still be extended though).

Mark showed some short videos during his presentation which demonstrated how clients' gait, and therefore their safety while walking, could be improved by the prescription of an appropriate orthotic, individually tailored for their particular disability. Some of the improvements seen were quite dramatic.

After a question and answer session, Committee Member Bill McKee thanked Mark for giving up his Saturday to share his knowledge and expertise with members, and presented him with a pen hand-crafted from Australian wood as a memento of the occasion.

Post-Polio Network Office Co-ordinator's Report

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**George Laszuk
Office Co-ordinator**

Greetings from the staff and volunteers at the Parramatta Office, we hope you are all well and coping with the winter chills.

As I reported last time we lost the services of two of our volunteers who moved on to other pursuits. With the assistance of Volunteering NSW we have been able to recruit two more very capable people who bring with them excellent office and administration skills. Our first recruit was Ray Holmes who lives in Merrylands and commenced with us in March. In April Shylie Little from Baulkham Hills joined us.

Our roster had to change due to the new incoming volunteers and also Nola Buck is currently away on holidays (in the warmer parts of Australia) for approximately 3 months. Our current roster is as follows, from 10:30 am – 3:30 pm, Monday to Friday.

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

During the past few months we have been very pleased that more of our members and other interested parties have utilised our office at Parramatta. For example, we have been able to refer people to services onsite that Northcott or the Independent Living Centre can provide, or make enquiries on their behalf further afield if necessary. We also have had university students visit us wanting information about polio and its late affects; one of these students whose father had polio as a child came all the way from Japan.

Our biggest challenge in keeping our office viable is funding, and as you are probably aware we receive no government assistance and rely solely on membership subscriptions and donations. Donations are always gratefully received (as well as being tax deductible to the donor). The funding dollar is getting more and more difficult to secure and unfortunately we learned recently that one of our major sponsors can no longer provide support after this year. The members of our Committee are nearly all polio survivors and are getting on in years, therefore their ability to continue the huge work load that is required to run the Network is diminishing. At the same time it is vital that the office at Parramatta continues to be an integral part of the Network's ability to service our members and relieve various tasks from overworked Committee members. The office also provides an accessible location for members to visit and provides our Network with a sense of identity in the eyes of the public.

I hope you all keep well and that I can catch up with you in person at a Seminar later this year.

The Network is Named Small Business Employer of the Year

Northcott's employment service Jobmatch held *The Inaugural Jobmatch Employer of the Year Awards* on Tuesday 17 July 2007. The Awards were created to recognise businesses that employ people with a disability.

There were three categories for employers to enter: small employers with 10 or fewer full-time employees, medium employers with between 11 and 200 full-time employees and large employers with more than 200 full-time employees. There was also an overall Employer of the Year Award.

To be considered as a finalist, applicants were judged on the number of employees with a disability, integration of employees with a disability and career planning for employees with a disability.

Manager of Jobmatch Patricia Tomlinson said the awards were part of an overall marketing plan to ensure Northcott's Jobmatch service was promoted to the wider business community. *"Northcott's Jobmatch service aims to provide people with disabilities the support they require when looking for a job. Qualified staff provide clients with pre and post employment support, together with consultative services to employers to facilitate an environment appropriate for a person with a disability"*, Miss Tomlinson said. *"We would like to acknowledge employers who are willing to give people with disabilities a fair go. Without acceptance and inclusion in the workplace, many of our clients will not reach their individual goals."*

As one of the three finalists in the Small Business category, the Network was delighted to be declared the winner. Pictured below are the Award glass sculpture and President Gillian Thomas accepting the Award on behalf of the Network from Mike Fryer, Director of Operations, Northcott Disability Services.



Modern Technology

Gary Buchanan

One of my regular correspondents is member Gary Buchanan. A couple of months ago he wrote in part: "My health has taken a nose dive and I must say I have been very ungracious in accepting that fact. I've always accepted the fact that physically over time I would deteriorate but never gave health much thought, then again I never gave ageing much thought also! Why is it that youth has to be wasted on the young?! Last week I had a visit from an occupational therapist regarding my situation and could not help afterwards capturing it in writing."

Last week I was paid a visit from a lovely lady named Jodie who is an occupational therapist connected with Bankstown Hospital, accompanied by her male colleague. The purpose of this visit was to ascertain if I had the necessary equipment to survive at home as well as checking whether railings for the front and back steps would be of assistance.

After the usual introductory conversation and we had settled down for a chat, Jodie asked me what sort of therapy I originally had in hospital as a child to get the muscles back working in my hands and fingers of which I remembered quite well.

Initially I was taught how to weave cane baskets and trays, then later how to make leather wallets then how to knit a scarf.

I remember when I started basket weaving and was getting positive comments from the visitors who came to my ward that I had a flash of marketing initiative and set myself up in business as a supplier of all my hand made goods.

The baskets I charged five shillings for, the trays seven and sixpence and the wallets were nine and nine pence.

When I was finally discharged I had amassed a fortune of just over twenty pounds, almost enough to buy a block of land with!

My knitting experience though was a bit different because as a well meaning gesture of a shared project the nurses, many visitors, the cleaning staff and physiotherapists would bring me any spare wool they had in their possession and as it happened the scarf just grew and grew and grew. Everyone viewed it as a supplement to Joseph's coat of many colours. You can imagine after eighteen months how long it became, it even reached the next ward.

On my final departure from my place of business the ward sister asked if I could leave the scarf in her care so she could get other young patients to keep it going. I really think she just wanted to get a mention in the Guinness Book of Records.

Following those innovations Jodie said, "WOW! That must have been yonks ago as I was told at the beginning of my training I would probably be referred to as a weaver as that was what therapists who taught many years ago were referred to as, but these days we train rehab with much more modern and practical methods."

I immediately then asked what were the new modern methods people with arm and hand disabilities practised and was told, "We get them to screw nuts onto bolts and things like that."

There is something to be said about the new methods although not in public and I'm sure if I had practised nut and bolting I wouldn't have acquired the commercial success I then enjoyed with basket weaving and leatherwork.

Now I guess I should pretend to be a nut and bolt.

Support Group News

Neil von Schill

Support Group Co-ordinator

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Due to my commitment to and involvement in the organisation of the Polio Australasia Conference at Northcott early in May, I have unfortunately not been able to maintain my regular personal contact with our many Convenors and Support Groups as I would wish to do. Hopefully this will change over the next six months.

Members and particularly Convenor, **Rosalie Kennedy**, of the **Northern Rivers Support Group** have been busily preparing for this year's **Country Conference** which will be held at **Ballina RSL Club** on **Saturday, 15 September 2007**. If you live in the northern part of the state or are a traveller please put this date on your calendar. Full details appear on page 4 of this edition of *Network News* and a Registration Form is enclosed as appropriate.

On **Wednesday 11 July** the members of the Management Committee hosted a luncheon at Northcott to recognise the work of Convenors and volunteers to thank them for their commitment to members and to the Network. There was a good turnout and the room was abuzz with conversation as those attending took the opportunity to meet other Network supporters for the first time.

Just to switch to my Secretary hat for a moment, in an endeavour to expand the role of the Network Office and make it more functional and effective and to reduce some of the workload of Management Committee members, we are training our Administrative Assistant, Carlie O'Reilly, to perform the role of Minutes Secretary for Management Committee meetings. Carlie has now attended several meetings and is quickly and willingly learning the skills for the position. This initiative will be a boon for future Network Secretaries.

Age Eligibility for CAAS Extended

The Commonwealth's Continence Aids Assistance Scheme (CAAS) offers help to people who have permanent incontinence due to a neurological condition or intellectual impairment. CAAS helps eligible clients to meet the cost of continence aids. Previously, applicants for CAAS had to be between 16 and 64 years of age (unless the person aged 65 years or over was in paid employment for at least eight hours a week). From 1 July 2007, age eligibility was extended to eligible people aged 5 years and upwards. Eligible CAAS clients must qualify for the Disability Support Pension, Mobility Allowance or be in receipt of the equivalent Tax Exemption on a vehicle. People 65 years and over will need to meet eligibility requirements deemed equivalent to the DSP, but will no longer need to be in paid employment. CAAS is administered on behalf of the Australian Government by Intouch Direct, the commercial arm of the Spinal Injuries Association. CAAS provides up to \$470 per year on continence aids ordered through Intouch. People who received CAAS but left the scheme after they turned 65 are eligible to re-apply for funding from 1 July 2007.

Polio Particles

Mary Westbrook

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



Search for a biomarker marker of PPS

Biomarkers are biological signs of particular diseases which are a help in making a diagnosis. PPS is often referred to as a diagnosis of exclusion. Many other diseases have similar symptoms to PPS making diagnosis of PPS complex. Doctors may disagree as to whether a patient has PPS. Post-Polio Health International (formerly GINI) has made a grant of \$US25,000 to a research team at the University of Arkansas to assist them in their search for a *unique signature, or disease biomarker, in the immune system of individuals with post-polio syndrome that would enable a more definitive diagnosis of PPS.* The Winter 2007 edition of their newsletter *Post Polio Health* reports that the team has *recently detected the presence of a distinct immune cell in the blood of individuals with PPS but not in healthy individuals, although the number of donors examined was small. The detected cells represent a recently described subtype of T cells, known as regulatory T cells (Tregs). The research award will fund a small pilot study that will determine whether development of PPS is associated with increased numbers of Tregs, and whether the Tregs found in individuals with PPS have unusual properties.* Joan Headley, Executive Director of Post-Polio Health International, says that *a definitive test for PPS would not only help with diagnosis but would also help develop potentially more effective therapies.*

Murder of doctor heading anti-polio campaign

Dr Abdul Ghani Marwat headed the Pakistani government's vaccination program in Bajaur near the Afghanistan border. Rumours that the campaign was a western conspiracy to sterilise Muslim populations are rampant in the area, often spread via radio or loudspeakers of mosques. In February on his way home from attending a meeting with local religious leaders about the need for children to be immunised, Dr Marwat's vehicle was hit by a bomb which killed him and injured three health workers. The following week 1,500 health workers in the region wore black armbands and went on strike to protest. The Pakistani *Daily Times* (20/2/07) quoted a Health department official as saying that the strike was to last three days *"to protest against the lack of security for health workers in the region. The health workers have also decided to boycott the three-day vaccination program beginning from Tuesday and they will take out a protest rally in Khar"*. Local health officials said some 140,000 children could be affected by the action.

Some conservative religious leaders in Pakistan such as Maulana Fazullah are warning their communities that *finding a cure for an epidemic before its outbreak is not allowed in Sharia* [Islamic law]. *According to Sharia, one should avoid going to areas where an epidemic has broken out, but those who do go to such areas and get killed during an outbreak are martyrs.* Many of Pakistan's more moderate imams and scholars have issued a fatwa [religious ruling] encouraging vaccination. According to the *Hindustani Times* (11/3/07) the Pakistani Health Department is appealing to Hajis who have just returned from their pilgrimage to Mecca to persuade Muslim families to take their children to vaccination booths. The chief immunisation officer in the areas with the worst vaccination rates said: *It will create more impact on Muslim families when the Hajis will share their*

experience regarding mass-scale immunisation of children against polio, in Saudi Arabia and other Gulf countries.

Good leg, bad leg

Polio survivors whose lower limbs were affected by the disease almost always refer to their 'good' and their 'bad' leg. With the onset of the late effects of polio they often express shock and outrage at the way their 'good' leg is letting them down. Anne Finger, an American polio survivor, has just published *Elegy for a disease: A personal and cultural history of polio*, a book which interweaves her own polio story with that of the disease. In it she describes her reactions to the diagnosis of PPS.

I moved from the liminal space that straddled identities, my left leg in the world of the normals, my right foot in the world of cripples. My body, as well as my social identity, had been bifurcated: I had a good leg and a bad leg. Sometimes I personified those two sisters who were my lower limbs, my good girl and my bad girl, as Sonya and Claire. Sonya, the stalwart left leg, and Claire, the loose and giddy right one. Sonya might play the role of an exhausted mother or a beleaguered elder sister in a Russian black-and-white movie about World War II ... And Claire? She was a flapper, swinging through life free and easy, never doing any work, just along for the ride. ... when I was having circulatory problems in my right leg, a doctor said to me, 'I can't promise that you're not going to lose that leg', that had seemed perfectly apt. Claire was a gal who might go out for the proverbial pack of cigarettes one night and then – one thing leading to another and then another – get herself lost, never come home. As for Sonya – she was one of those overburdened women whom middle age hits like a body blow. After doing double duty all these years she sinks into her chair at the end of another hard day and sighs, 'I can't believe how tired I am ... They did an X-ray – bilateral hip, and what do you suppose it showed? Well, frail Claire who's done sweet f—k—all all these years – clean and smooth. Does she show any arthritic changes? Ha! But me – I've just been worn down by it all. You can see it, right there in black and white ... See. There's my suffering. Plain as day. No one can deny it.' Finger's book, which is a very good read, was published by St Martin's Press, New York, in 2006. It is available from Amazon.com for \$US18.94 plus postage.

Billions saved by polio vaccination

A research report has shown that the polio vaccination program in the USA resulted in a net savings of over \$180 billion, even without including the large intangible benefits associated with avoided fear and suffering. The authors found that the US invested over \$35 billion between 1955 and 2005 and will continue to invest billions into the future to pay for polio vaccination. They estimated that these historical and future investments translate into over 1.7 billion vaccinations and prevent approximately 1.1 million cases of paralytic polio and over 160,000 deaths, thus saving Americans hundreds of billions of dollars in treatment costs. Dr Stephen Cochi from the US Centers for Disease Control is quoted as saying, *This study documents the extraordinary power of vaccines not only as highly effective tools to prevent disease, disability and death, but to provide enormous economic savings to society.* The research was conducted by the Harvard School of Public Health and published in the journal *Risk Analysis* in December 2006. (Quotes from *Newswise.com* 19/1/07)

Airport search nightmare for polio survivor

Diane Kirlin Murphy is an American polio survivor who wears two long leg braces, walks with forearm crutches and when she is at an airport uses a wheelchair. On a recent trip from San Francisco to Philadelphia she was told to wait at the security checkpoint. In a letter of complaint to the Transportation Security Administration (TSA) she described what happened. *After a full body pat-down, I was told I could not be cleared to fly until I*

submitted to further inspection of my legs and braces ... I was told to drop my pants, while they offered to hold up a sheet ... At this point I refused. I cannot physically stand and drop my pants while maintaining my balance ... The TSA would not give me my crutches or my handbag because I had not been cleared. I was told that I could not fly if I did not submit to the search and ... that I could not go to the bathroom until I was cleared. By now I was swelling with outrage and in tears. I had no choice but to submit to the humiliating and demeaning search by two female security officers. They reluctantly agreed to allow the search to be conducted in an adjoining ladies room.

TSA answered Diane's letter and offered a *sincere and deepest apology*. ... An investigation of this incident ... revealed that they [the transport security officers] had applied the wrong procedure, explosive trace detection (ETD) sampling to your leg brace ... Whenever a person wearing a support appliance alarms the walk-through metal detector, they must undergo additional screening. A visual inspection should be conducted on the exterior accessible area of the support appliance, the areas that can be assessed by a person lifting his/her pant leg, shirt sleeve, or raising a skirt to knee-level. If no area can be assessed, a limited pat-down will be conducted to ensure no prohibited items can be concealed. At no time during the process, should you be required to remove your support brace or remove your clothing. ... The exact screening procedure depends on whether the individual can stand and walk, only stand or not stand at all. TSOs are taught to offer a private screening for the pat-down inspection. ... Walkers, crutches, and canes that can fit through the machine must undergo x-ray screening ... TSOs should have allowed you to have your cane once it had cleared to assist you during the screening process. This incident was reported in the Winter 2007 edition of Post-Polio Health and the correspondence is on their website <www.post-polio.org>.

A use for 'tamed' polio virus

In the March issue of the journal *Cancer Research* Dr Hidemi Toyoda and colleagues, of the State University of New York, reported their research into mice with neuroblastoma, one of the commonest childhood cancers. The researchers developed mice that were susceptible to polio, immunised them against polio, and then injected them with neuroblastoma cells. When the cancers had grown to about 170 cubic millimetres half of the mice were injected with a saline solution and half were injected with highly attenuated poliovirus on four consecutive days. Eight days later, the tumours in all the saline injected mice had increased in size significantly but the tumours in the mice who received poliovirus had reduced on average to 128 cubic millimetres. None of the polio injected mice showed any signs of paralysis. By 180 days after the injections the cancers in 9 of the 11 mice that were given poliovirus had completely regressed. Six months later these mice were reinjected with neuroblastoma cells but none developed tumours. Dr Toyoda said, *This immunity against neuroblastoma acquired by the animals is still something of a mystery, one that we hope to address in future studies. But it is an encouraging sign since neuroblastoma are known to relapse quite frequently ... A tamed polio virus represents a significant step in finding viral treatments that can kill tumors without harming patients. Effectively, we have harnessed a virus that was deadly in children, just a few decades ago, namely polio, and used an essential aspect of its nature to destroy a disease that is deadly today.* (Information from <www.medpagetoday.com> 16/3/07)

New polio vaccine more effective in India

On 21 April the British medical journal, *the Lancet*, announced research findings that a new polio vaccine, mOPV1, is more effective than the standard vaccine in protecting children in northern India from polio. The poor sanitation in India helps the spread of polio and the fact that children often have diarrhoea and other infections when vaccinated hinders the effectiveness of vaccination. mOPV1 is a high potency vaccine that was developed for and

introduced into India in 2005. It only targets the most common strain of polio, type 1, as *the efficacy of trivalent vaccines can be diminished because different strains of poliovirus interfere with one another in the body, sometimes producing immunity to one strain but not another.* There have been no reported cases on type 2 wild poliovirus in the world since 1999. The research shows that *the clinical efficacy of the monovalent vaccine in this difficult setting [India] is about three times that of the trivalent vaccine against type 1.*



Poet's Corner

It Can't Be Done

Roger Smith
ACT Post-Polio Support Group
December 2006

Whatever the situation throughout this land today
Some people blame the government for all that comes their way
Federal or State matters not from the hip they often shoot
As long as they can have a whinge and then lay in the boot
Now it could be about low wages and the hours they have to work
Of inconsiderate bosses and of those who only shirk
And then when they are in their homes with comforts there galore
They listen to the talk backs and they whinge some more
They really do complain a lot of taxes and IR Laws
Of the Education system and point out all its flaws
And the government cops much criticism of hospitals and aged care
Of the shortage of nurses and dentists, that are needed everywhere
Petrol prices are so high why can't they bring them down
Or provide us with more childcare places needed in our town
Every day people can be heard on talk back radio
Trying to tell the governments how to run the show
Now with many of the criticisms I really must agree
For many of the decisions affect both you and me
But to live in great Australia I think we should be proud
And readily support it in tones both clear and loud
But there is one thing of governments I think it only true
Though they'd probably really like to see what they could but do
Then if they tried I do believe their efforts would be in vain
Cause in this drought of 100 years they cannot make it rain.



Post-Polio Network Seminar Program 2007 / 2008

Saturday 15 September 2007	Ballina RSL Club <i>Ballina Northern NSW</i>	Biennial Country Conference – Ballina <i>For full details including the Presenters and Topics please see page 4 of this Network News</i>
Saturday 17 November 2007	Burwood RSL Club <i>96 Shaftesbury Road Burwood</i>	Annual General Meeting and Seminar <i>Further details in upcoming issues of Network News</i> Please note the change of both date and venue
Saturday 1 March 2008	Northcott Society <i>1 Fennell Street Parramatta</i>	Seminar the Presenter and Topic to be advised <i>Further details in upcoming issues of Network News</i>

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About the Network

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

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

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

If you live in Australia, we can post you a free Information Kit and Membership Application Form. The Kit includes a copy of our booklet *Helping Polio Survivors Live Successfully with the Late Effects of Polio* which explains the late effects of polio and details the many benefits of Network membership. This booklet can be emailed to those enquiring from overseas.

The annual membership subscription (payable in Australian dollars only) is \$10 not employed or \$20 employed. On first joining, new members also pay a \$5 once-off joining fee. Those initially joining between 1 April and 30 June in any year are deemed to be financial until 30 June the following year. Membership renewal is due on 1 July each year and members are alerted to their financial status with each Network mailing. Over 80% of the Network's income which is used to provide its services comes from membership subscriptions and donations.

Resources for Members

On joining the Network, members are issued with free resources including a brochure *Hospital, Medical And Dental Care For The Post-Polio Patient – A Handy Reference*, and a Medical Alert Card which can be carried in the wallet.

The Network also stocks various publications which further describe the late effects of polio and their management. The prices quoted below are for Network members and postage is included. To order, just write to the Network – please make cheques / money orders payable to Post-Polio Network (NSW) Inc.

Books etc (* indicates Post-Polio Network publication)	Size	Cost
<i>Managing Post-Polio: A Guide to Living Well with Post-Polio Syndrome</i> edited by Lauro S Halstead MD (<i>see description below</i> 📄)	240 pages	\$25.00 <i>plus 10% GST</i>
<i>A Practical Approach to the Late Effects of Polio</i> Charlotte Leboeuf	39 pages	\$2.50
<i>The Late Effects of Polio: Information for Health Care Providers</i> Charlotte Leboeuf	56 pages	\$2.50
* <i>Living with the Late Effects of Polio</i> Conference Proceedings, edited by Gillian Thomas	170 pages	\$29.00
* <i>Polio – A Challenge for Life – The Impact of Late Effects</i> Report: Survey of Members, Merle Thompson	54 pages	\$12.00
* <i>Post-Polio Network - Helping Polio Survivors Live Successfully with the Late Effects of Polio</i> , Dr Mary Westbrook	12 pages	\$3.00 <i>1st copy free</i>
The Network has its own four-colour enamelled badge featuring a stunning polio virus design. The badges are suitable for men or women. Each badge comes with a description of the virus and information about the Network. Not only is the badge a great fashion statement, it is an innovative way to promote the Network.	23 mm x 23 mm	\$5.00 <i>plus \$1 postage</i>

📄 ***Managing Post-Polio: A Guide to Living Well with Post-Polio Syndrome***

This 240-page book provides a comprehensive overview on dealing with the medical, psychological, vocational, and many other challenges of living with post-polio syndrome. Written by 20 authorities in their fields, the majority of whom are polio survivors themselves, *Managing Post-Polio* distils and summarises in lay terms the wealth of information presented at conferences and published in the medical and allied health literature over the past 10 to 15 years. This information is supplemented with personal stories of seven individuals who provide eloquent testimony to the many ways people have prevailed in the face of ongoing disability.

Intended for persons who have had polio, their families, friends, and loved ones, *Managing Post-Polio* was also written for health professionals who are unfamiliar with the late effects of polio and those who would like to learn more. As Dr Halstead, a polio survivor himself, observes in the introduction, "this book was written and edited partly to help me deal better with my own unique disability and to help the many thousands of other polio survivors in this country and around the world deal more effectively with their unique version of polio disability."

Audio tapes of many of the Network Seminars and Conferences held since 1989 are also available at reasonable prices. For further details please contact the Network.