



POST - POLIO NETWORK (NSW) INC.

NETWORK NEWS

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President's Corner

Gillian Thomas

Welcome to regular readers and new members alike. Our **Mini-Conference** on **16 December** has attracted a lot of interest from members. As I write we have 85 people registered to attend. Participants will hear Melbourne Rehabilitation Consultant **Dr Stephen de Graaff** speak about the late onset effects of polio and management aspects. The Mini-Conference which will commence at **9:30 am** promises to be an event not to miss, and lunch is included for the small registration cost of \$10 per person. **You must act now if you wish to come along – full details of the day appear on page 2.**

Remember too that our **Annual General Meeting** will also be held on **16 December**, commencing at **2:15 pm**. The AGM is your chance to contribute towards running the Network for the benefit of your fellow polio survivors. As Committee members stand down, we need others to take their place – please think about standing for the Committee. Our volunteers are the backbone of the Network – without their dedication and commitment the Network would cease to exist. Therefore, at the conclusion of the AGM, we are holding a special ceremony to celebrate the Network's volunteers and show our appreciation for their work.

Since the last *Network News* was published, we have learned that the Department of Ageing, Disability and Home Care's "Expression of Interest" process which was to fund advocacy and information services in New South Wales has been halted, permanently. This means that the weeks of work that we put into preparing a detailed funding submission has been virtually wasted. We were naturally bitterly disappointed with this outcome – the process was aborted before our application was assessed on its merits. The work on the submission diverted our meagre volunteer resources away from our primary purpose, providing information and support to polio survivors, but was necessary because the Network needs ongoing funding to ensure its long-term survival. In recent weeks the Department has commenced a new process. In order to even be in the running for the \$1 million funding available for advocacy and information services, we now have to submit a new, again very comprehensive, "Request For Proposal". The submission is due in on 18 December, just two days after our Mini-Conference / AGM, so we are certainly juggling a lot of balls at the moment.

We look forward to meeting up with many members, including a good proportion of our Support Group Convenors, on 16 December. The Management Committee joins me in wishing all our members and friends a Happy Christmas and a Peaceful New Year.

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Post-Polio Network

Mini-Conference / Annual General Meeting

Date: Sunday, 16 December 2001

Time: 9:30 am - 4:00 pm
Refreshments and lunch will be provided

Venue: Regency Function Centre
Burwood RSL Club
96 Shaftesbury Road
Burwood NSW

The venue is readily accessible for those in wheelchairs or with mobility difficulties and there is ample parking. There are lifts from the car park Basements 1 and 2 to the Function Centre on Level 1.

For those catching public transport, the RSL Club is approximately a 500-metre walk from Burwood Railway Station.

Registration: As the Network is subsidising the Mini-Conference, the registration cost is only \$10. **If you have not yet registered but would like to attend, please call Gillian on (02) 9663 2402 or Alice on (02) 9747 4694 as soon as possible so catering arrangements can be finalised.**

Dr Stephen de Graaff MBBS FAFRM, Consultant Physician in Rehabilitation Medicine, will present the two Keynote Addresses and conduct the Question and Answer Session. See page 3 for a profile of Dr de Graaff.

- 9:30 *Registration and tea/coffee*
- 10:00 Late Onset Effects Of Polio: Are They For Real?
- 11:00 *Morning Tea*
- 11:30 Is Pain Necessary in Polio Survivors?
- 12:30 *Lunch*
- 1:30 Question and Answer Session – You Were Asking?
(written questions collected over morning tea and lunch)
- 2:10 *Break*
- 2:15 Annual General Meeting (see separate sheet for the Agenda)
- 3:15 *Afternoon Tea*
- 3:30 Celebration of Volunteers
- 4:00 *Finish*

Dr Stephen de Graaff

Dr De Graaff is a Consultant Physician in Rehabilitation Medicine. He is currently Chief of Rehabilitation Medicine at Cedar Court Healthsouth in Camberwell Victoria, and Head of the Neurological Rehabilitation Unit at Caulfield General Medical Centre. Dr de Graaff is Chairman of the Board of Continuing Education within the Australasian Faculty of Rehabilitation Medicine, past Chairperson of the Victorian Branch of the Australasian Faculty of Rehabilitation Medicine, and member of the Executive of the Australasian Faculty of Rehabilitation Medicine. Dr de Graaff's interests include neurological rehabilitation and musculoskeletal rehabilitation pain management in the areas of stroke, acquired brain injury, multiple sclerosis and polio. Dr de Graaff has a particular interest in combining the neurological and musculoskeletal management of polio survivors.

Post-Polio Syndrome Orthotic Care Presents Challenges

Miki Fairley

This article was published in "O & P World", Vol 4, No 3, July/August 2001, and the Network is grateful to be able to reprint it here. The points made in the article are just as relevant to an Australian audience as to an American audience. Thanks are due to member Casper Ozinga, Comfort & Fit Australia Pty Ltd, Parramatta (specialists in orthopaedic and comfort footwear) for first bringing the article to our attention.

What problems are confronting polio survivors who are now dealing with post-polio syndrome (PPS)? "What drives many of these patients to their physicians and eventually to orthotic facilities is pain", said Mark Taylor, CPO, University of Michigan Orthotics & Prosthetics Center, Ann Arbor, Michigan USA, in a presentation during the recent Annual Meeting of the American Academy of Orthotists and Prosthetists (AAOP). "In a way pain is good: it is a tool by which a patient can be protected from further damage if he/she listens", he added. Joining Taylor in a series of sessions on PPS at the Academy meeting were David J Forbes, CPO, FAAOP, Rochester Orthopedic Laboratories Inc, Yorkville, New York USA; and Stephanie Langdon-Bash, CPO, FAAOP, immediate past president of the Academy.

The increase in debility for these patients has been gradual and undramatic, with patients experiencing more fatigue and unsteadiness and falling more often, Forbes noted.

"A fixed or increasing deformity, such as equinus or recurvatum, may add to their concern, pain and loss of function", Langdon-Bash said. Patients often have undergone years of postural substitutions for weak muscles, concentrating forces on mature joint tissues, thus resulting in painful stresses, she said, adding that joint surfaces may have been remodeled if these deforming forces were present in a growing child. "Recognizing the patient's symptoms as evidence of chronic strain provides a rationale for both therapeutic design and patient acceptance."

Because of their spared sensory neurons, polio patients are able to substitute for the paralyzed musculature, she noted, adding that their functional ability is extended by substitutions and changed posture which transfer some of the demand to stronger muscles and ligaments.

Gait deviations are a common symptom. Gait deviations fall into two categories: useful substitutions and functional inadequacy, Forbes pointed out. "Useful substitutions, however, can lead to symptoms when the substituting muscles are overused; they also then require orthotic assistance."

Orthotic Goals

The orthotic goal to halt increasing debility may be to stop the motion at a joint to compensate for failing compensatory motion in order to increase safety and stability, improve walking ability and perceived walking safety with less overall pain, according to Forbes.

Effective orthotic management must combine support for a deformity, substitution for muscle weakness, and removal of stresses with freedom of movement, Langdon-Bash pointed out.

“Evaluating the patient fully and taking notes will help you to design and fabricate an orthosis to meet the polio patient’s needs”, she said. “We want to be careful not to transfer these stresses or demands to another part of the body, like the arms, back or other leg.” She listed goals for bracing these active people as:

- correcting or accommodating and preventing deformity;
- supporting the limb for stability;
- decreasing the stresses placed on the joints;
- decreasing the energy expenditure that is causing the muscles to become fatigued;
- and to normalize the gait pattern, since normal gait is the most energy-efficient and least stressful way to walk.

If possible, joints need to be protected to prevent further damage while allowing the patient to continue to have mobility, Taylor said, adding that by providing stability and more normal biomechanical function, joint destruction and muscle fatigue can be reduced.

Evaluation

It is important to identify the source of the pain, Taylor said, adding, “Orthotic professionals need to focus on the musculoskeletal issues.”

A thorough examination of the patient, including a history of previous orthotic use and of current ambulation problems, especially frequency and causes of falling, is very important to formulating an orthotic prescription, Forbes pointed out, noting that if an orthosis is improperly designed it may not only be uncomfortable or cumbersome but may actually interfere with important compensatory motions with severe implications.

“We, as professional practitioners, need to take the time to listen and to properly evaluate these patients’ conditions”, Forbes said. “It is imperative that orthotic practitioners become familiar with the polio patient’s history. Practitioners need to understand exactly what it is that they are dealing with. They need to know at first hand what the patient’s muscle weaknesses and range of motion are and how the patient is substituting for the weakness in order to function.”

“An effective evaluation will provide a clear estimation of the probable functional ability of the patient and the sources of deformity in need of support”, Langdon-Bash said. The patient as a whole needs to be carefully evaluated, so that the strains of overuse are not redirected to another affected muscle group, she pointed out. According to Langdon-Bash, a thorough evaluation of the patient should include:

- a gait evaluation to note function deviations;
- muscle testing for the strengths as well as the weaknesses;
- and evaluation of range of motion of the involved joints, looking for excessive movement and fixed deformities.

- Psychological and emotional issues need to be considered when evaluating the patient and designing an orthosis. The prescription for the post-polio patient is a problem, not only because of the patient's physical condition, but also because of his/her experience with orthotic devices in the past, Taylor noted. For instance, the patient may have rejected orthoses in the past and may not be willing to accept an orthosis - a public sign of disability - now. The patient may have worn a certain type of orthosis for years and may be unwilling to change.

How can an orthotist meet this challenge? "In-depth discussion with patients in which you outline the design of the orthosis and what you wish to accomplish is critical", Taylor said. "You must also find out what they want to accomplish. Most fear the new loss of function and what lies ahead for them." Time with these patients is important for outlining objectives and design criteria, he added, noting that the need for compromise and "tailoring" of the orthosis must be kept in mind.

"It is often difficult to determine the real needs of the patient, and the practitioner may find himself imposing his misconception of the problem on the patient, to their mutual frustration", he warned. Using an orthosis implies that the patient has to accept the disadvantages as well as the advantages, he noted. "It is important to maximize the advantages and minimize the disadvantages to win approval of the orthosis."

A recent problem confronting orthotists in the US is that many PPS patients requiring orthotic care are reluctant to confide in their orthotist, Taylor said. They have been told by many orthotic professionals that they are hard to deal with, that they are set in their ways, and that they take a considerable amount of the orthotist's time. "The orthotic profession must be careful not to prejudge these patients as all of one type of personality", he advised.

Orthotic Design

Orthotic design for PPS patients presents a challenge, Forbes and Langdon-Bash said, noting that, to be effective, it must accommodate the patients' substitute mechanisms as well as their instability and deformity.

"The polio patient is the most important part of his/her rehabilitation team", Taylor pointed out. Polio patients must be allowed to assist in the design of their orthoses, he said, adding that patients also need to realize that orthotists are trying to provide a system that will protect and stabilize. "Be flexible with these patients", he said. "Leave options in the treatment plan. Provide patients with a choice and lead them in the right direction. Let them know that your abilities and expertise can help eliminate unwanted range of motion and allow for a more normal function." Taylor advised practitioners not to lock the joints on their orthoses unless absolutely necessary. If joints are locked, the device might end up unused in the closet, not because of the design, but because "you have taken away from them the simple motions that they use to substitute for muscle weakness and joint deformity."

Younger and stronger patients often accept more aggressive designs and seem to be willing to allow more time to adjust to new designs, Taylor said. "They seem to have a better understanding of what the intended outcome is and will work to make it happen, if possible." Older patients' conditions are often more complex, due to additional muscle and joint fatigue. "They seem to be more apprehensive about change", Taylor noted. Orthotic practitioners need to realize that these older patients have experienced much, and some of that experience has dealt with past orthotic challenges, he pointed out. "These patients need to lead the way, and they are also the ones who need options to choose from."

Elderly ambulators need lightweight orthoses, plus they don't like too many changes. "Practitioner listening skills need to be especially keen for this group", he said, adding, "You must let these elderly patients know that you care about them, and you must learn to take their criticism with a smile."

Taylor encouraged practitioners to consider all design options available to them. Some options may be a combination of two or more orthotic designs. "For example, you may have a patient that needs additional knee stability due to weakened quadriceps but is unable to tolerate the weight of a conventional design. One idea is to provide a hybrid orthosis consisting of a leaf spring design with a pretibial shell which provides minimum quadriceps support and gives just enough feedback to prevent the knee from buckling.

"Many new and amazing materials are becoming available to the orthotic professional", Taylor continued. "This allows for lighter and stronger designs. New techniques are also available through the modern technology of orthopedic surgery. Some joint deformities can now be improved dramatically, relieving stress and pain from joints and surrounding tissue. Keep your polio patients informed and don't be afraid of the challenge. You have been trained to provide your area of expertise to these patients who are becoming more and more reliant on your professional services."



Second Best

© Jude King

Jude is a polio survivor with PPS and a member of the Central Maryland Post Polio Support Group in Columbia, Maryland, USA. This poem is from her Anthology of Poems "Body and Soul" and is published here with Jude's kind permission. Requests to reprint her poem "Second Best" should be sent to Jude at <heyjude2425@home.com>.

"Just try a little harder, don't be second best!"
Though I am a little smarter, that's not a fair request!
I wish that I could tell them, how I long for them to know
I'm behind before I've started, 'cause I had Polio!

For me life's rules are different, Why? I still don't know.
I'm not allowed self pity, and challenge makes me go,
And most of the time I've "pulled it off" so well you'd hardly know
There's any handicap at all, 'cause I had Polio.

The problem is, I'm wearing out from years of trying hard.
It's like I've run a marathon and missed the finish by one yard.
Now I must learn to take life easier for reasons that don't show,
And my good seems "not good enough" 'cause I had Polio.

I'm not asking for excuses, or even sympathy
All I'm really claiming is, permission to be me.
Yes, I must strive for excellence, just want someone to know,
Mine may not be the same as yours, 'cause I had Polio!



Another Informative Guide to Coping with Post-Polio Symptoms

Mary Westbrook

Post-Polio Syndrome: A Guide for Polio Survivors and their Families by Julie Silver MD, director of the International Center for Polio in Framingham, Massachusetts was recently published by Yale University Press. Dr Silver's mother, brother and grandfather all contracted polio so the disease has always been part of her life. Her book comes three years after Lauro Halstead's *Managing Post-Polio: A Guide to Living Well with Post-Polio Syndrome*, which has been available to Network members for several years at a special rate. Inevitably the books will be compared. Silver's book of 280 pages is 40 pages longer than Halstead's and has 26 chapters compared to Halstead's 13. In Silver's book you can find specific chapters on virtually any post-polio relevant topic eg swallowing issues, nutrition and weight, respiratory problems, prevailing over pain, sex and intimacy, preventing falls, controlling cold intolerance, EMGs and bracing, shoes and assistive devices. It's harder to find relevant material in Halstead's book which lacks the excellent cross-referencing between chapters that Silver employs. If you want a practical, clear instructional guide you may prefer Silver. She gives *definite* doctor's orders on dealing with post-polio symptoms but also regularly instructs readers to seek their doctors' advice. If only there were Dr Silver clones around Australia that polio survivors could easily consult! If you prefer a more in depth discursive style which gives greater emphasis to the physiological causes and psychosocial aspects of post-polio then Halstead is your book.

Silver highlights many important practical issues that rarely receive attention. In the chapter *Preserving and Protecting Your Arms* Silver argues that *your arms are your key to independence. Think about it. If you cannot use your legs at all, you can still remain totally independent — living alone, bathing yourself, feeding yourself, driving a car. But if you cannot use your arms at all, you immediately cease to be independent and must rely on others to help you with the most routine (and intimate) activities of daily living.* She outlines three major causes of arm problems. Firstly, there is post-polio muscle pain, an aching, cramping, burning or tired feeling in the muscles rather than the joints. It often occurs at night or after activity. It indicates overuse and arms should be rested as much as possible. Secondly, there are soft tissue injuries such as muscle and ligament strains, tendonitis and bursitis. *Often these injuries occur in the arms from repetitive activities such as using a computer, chopping vegetables, knitting ... In polio survivors these types of soft-tissue injury occur frequently and often without an obvious reason. This is because many polio survivors have some upper body weakness (which may be subtle) that makes their arms more susceptible to injury. Also, polio survivors who have decreased lower-body strength tend to rely on their arms to assist them with mobility (as in getting up from a chair).* She urges medical, not self, diagnosis and treatment to avoid further and permanent weakness. Treatment may include avoidance of activities that exacerbate symptoms, ice, heat, splints, physiotherapy, occupational therapy, injections, medication and very occasionally surgery. Thirdly, there is biomechanical pain that usually presents as joint or neck pain. Silver says that such biomechanical pain is often attributed to arthritis and thought to be untreatable. Though arthritis may be present it may not be the major source of the pain. She has found that polio survivors frequently develop neck pain and headaches at the back of their heads due partly to poor posture and muscular strain. *Initial treatment may include improving one's sitting posture and avoiding neck strain, physical therapy, massage, heat, oral medications, and topical creams. If these treatments fail, injections may be useful.*

The chapter *Keeping Bones Healthy and Strong* differentiates generalised and localised osteoporosis in polio survivors. The latter often occurs in limbs that are paralysed or very weak. Such limbs are particularly vulnerable to fractures. Some survivors, like the able-bodied population, may develop generalised osteoporosis, which affects bones throughout the

skeleton. Silver has little advice on localised osteoporosis (probably because it is not well understood) but she discusses what can be done about generalised osteoporosis. She emphasises the importance of early diagnosis. In Australia this is often done by bone density scans of the spine and one hip. However a polio survivor needs to explain to the doctor about polio related localised osteoporosis or an inaccurate assessment may result. In my case I insisted that both hips be scanned. The hip of my weaker leg is very osteoporotic but the hip of the other leg and spine have better than average bone density.

Silver presents a practical 10-step plan for energy conservation and pacing. She quotes polio survivor Hugh Gallagher: *Growing old with polio is a matter of economics: cost/benefit analysis. How much expenditure of limited energy for how much satisfaction. Minimize the exertion; maximize the pleasure.* Silver suggests you start by keeping a log of activities for three days. Also document episodes of pain and fatigue, the time they occur and your activities around this time. Highlight low, moderate and high energy activities in different colours. Consider how high energy activities can be modified to become lower energy tasks. Lots of examples are given. Silver cites Josephine, a polio survivor, who is known to her family and friends as the *One-a-Day Girl* because she will only schedule one major outing each day. When friend contact her they ask, *Is your One-a-Day booked on such-and-such a day?*

In the chapter on exercise considerable emphasis is given to flexibility exercises. These are a critical *but often neglected part of any exercise program.* They can dramatically increase range of motion, and reduce pain and degree of disability. Again diagrammatic examples are given. Silver talks about reserve strength, which is something we count on to *sustain us as we age.* *In polio survivors, it is often markedly diminished and contributes to increasing disability that may present without much warning.* An example of reserve strength is given. *A certain threshold of strength is needed to do any activity. Imagine that it takes 30 percent of your total arm strength to lift a gallon of milk. This means that 30 percent is the threshold of strength your arm needs to lift the milk: if your strength falls below that mark you are unable to lift the milk. If you had polio and lost 50 percent of your strength, this is still an easy task to accomplish. ... you have 20 percent in reserve. But suppose through normal aging, disuse, overuse, and perhaps some other factors, you lose 1 to 2 percent of your arm strength each year ... when the amount of strength you have lost starts to get close to 20 percent, you are likely to notice that lifting a gallon of milk is becoming more difficult ... and if the next year you drop to 29 percent, you will go from being able to lift the milk to not being able to lift it.* Silver calls this the *all-of-a-sudden phenomenon* because polio patients often report such losses. The original bout with polio reduced our reserve strength and this contributes to the accelerated (compared to our able-bodied counterparts) loss of strength we experience as we age.

Some noteworthy comments from the book include: *“A syndrome is a collection of symptoms that characteristically occur together ... Because syndromes do not have specific tests that can unquestionably identify them, they are subject to interpretation. Often their validity is challenged within the medical community. PPS is no exception ... Generally it is inexperienced health-care providers, unfamiliar with treating polio survivors, who dismiss the syndrome. Those of us who routinely participate in the care of polio survivors have no doubt that PPS is real”. “Polio truly is a chronic illness that lasts a lifetime”. “It is important to recognize that some people may not have a classic history of polio but may indeed have had the disease. Moreover some of these individuals may be experiencing PPS”.*

Julie Silver's book is available from Internet bookshops *barnesandnoble.com* and *amazon.com* for \$US22 plus handling.

Editor's Footnote: Since preparing this article, Mary Westbrook has learned that some chapters of Julie Silver's book are available on the Internet (and other chapters seem to be going online in the future). You can find them at www.polioclinic.com/research.htm.

Change to Australian Privacy Requirements

Anne O'Halloran

Committee Member Anne O'Halloran has been representing the Network as it comes to grips with the implications and requirements of privacy legislation. Anne has prepared this article using information contained in "Draft Health Privacy Guidelines - A consultation document" issued 14 May 2001 by The Office of the Federal Privacy Commissioner.

On 21 December 2001 new legislation - The Privacy Amendment (Private Sector) Act - comes into effect. This includes National Privacy Principles (NPPs) which govern the collection, use, storage and disclosure of personal and sensitive information. The amendment includes the private health sector.

The new legislation will apply to any organisation that wishes to gain approval for its own privacy code as a replacement for the NPPs. The Act allows the Privacy Commissioner only to approve a privacy code if it offers a level of privacy protection for personal information that is at least equivalent to the NPPs.

What is "personal information"?

Personal information means information or an opinion (*including information or an opinion forming part of a database*) whether true or not, and whether recorded in material form or not, about an individual whose identity is apparent or can reasonably be ascertained, from the information or opinion. (*Section 6 Privacy Act.*)

Personal information can range from the very sensitive, for example, medical history, sexual preference or medical records, to the everyday, for example, address, phone number or hair colour.

What is "sensitive information"?

- Sensitive information is information or an opinion about an individual's:
- racial or ethnic origin;
- political opinion;
- religious or philosophical belief;
- trade union or professional association membership;
- criminal record; or
- health information

How is the Post-Polio Network involved?

The Network was invited to read and comment on draft guidelines of the amendment to the Act. These guidelines were very lengthy (*three separate sets of guidelines - approximately 368 pages in total!*). While we realise the importance of all the guidelines we decided to focus our reading on the document related to Health Privacy. There were many interesting components of the new legislation but because of space and interest we will only include here some of the key features.

One of the key features is that it provides individuals with a right to access health information held about them. This is set out in NPP 6. The Principle's objective is to let people know what information is held about them and the opportunity for the individual to have that information corrected where they believe that is not accurate, complete or up-to-date. A person with legal authority to act on the individual's behalf in regard to accessing their health record, may make that request. An individual cannot be charged a fee for requesting this information.

(The guideline elaborates on this feature and includes circumstances in which information may be withheld. Please see the web site address below for further information).

Another feature in the new legislation provides for the individual to take his or her records to a new health provider. In the past this has been difficult to arrange for some people.

Of interest to some members may be the special consideration on the use of identifiers (*defined as "a number assigned by an organisation to an individual to identify uniquely the individual for the purposes of the organisation's operations"*). The use of these identifiers provide for efficient handling of records, however there are some privacy risks. Identifiers can potentially allow for large quantities of information about a person from different sources to be brought together on one database. For your interest, the Network effectively manages its membership records without the use of such identifiers.

NPP 7 limits how a Federal identifier, for example, the Medicare number, may be used by other organisations. An organisation should not adopt for its own use a number assigned by the Federal Government.

In the new legislation there is a detailed section of *Use and Disclosure of Health Information* which includes that information that can be used for research and statistics. This applies to information that would identify the person. Most people are happy to provide information for research if that information and their identity is secured.

What is the Network's approach to the new legislation?

Post-Polio Network (NSW) Inc has always respected the confidentiality of its members (as embodied in its Constitution) and welcomes the National Privacy Principles.

At present the Network falls into the category of "*Organisations not covered by these guidelines*" and so we are advised to refer to the general NPP guidelines as our primary source of advice. For this reason the Management Committee has decided that it is unnecessary for the Network to develop its own privacy code. As well, if and when we receive any State Government funding, State laws on health and privacy will apply. However, the Management Committee has decided that a short statement about how the Network manages personal information should be developed. This statement would then be available to anyone who requests it.

The issue of consent to use information was also raised and members of the Committee felt that if the Network wished to use information that was identifiable, consent should be given in writing. Written confirmation gives the Network and the member greater protection if there is a later disagreement regarding what consent was given.

For more background on the Act, including information sheets, you can refer to the *New Privacy Law* page on the following Web site www.privacy.gov.au/news/pab.html.

Bits 'n' Pieces

- The Picnic Day with Sister Diadema and the Evangelical Sisterhood of Mary at Theresa Park on 17 November was a great success. More than twenty people attended, either taking advantage of the wheelchair-accessible bus organised by the Network, or travelling to Camden under their own steam. The weather was perfect and the Sisters were most welcoming. A full report of the day will appear in the next issue of *Network News*.
- Many members will remember Professor Richard Jones who has recently retired after more than 30 years at the Department of Rehabilitation Medicine at Prince Henry Hospital. Professor Jones has a deep affinity with polio survivors and has been a strong advocate for the Network over many years. Your President was delighted to be invited to his farewell afternoon tea. Watch out for the photo and full story in your next *Network News*.

Polio Particles

Mary Westbrook

Polio Particles is compiled by Mary Westbrook as items in the press or professional journals catch her eye. Included in this series are brief reviews of books on polio or post-polio, updates on post-polio research, information about immunisation and the status of global polio eradication, and other items of interest. Mary's series is now being syndicated around the world as other post-polio newsletter editors pick up on the interesting items Mary includes.

Transient Muscle Weakness in Polio Survivors

A symptom that post-polio researchers have ignored, according to Dr Richard Bruno, is transient weakness (*New Mobility*, April 2001). This occurs when you overdo and find that you can no longer carry out certain movements, or do them as well as usual, for example your limp becomes much more pronounced. The added weakness disappears after you rest for a day or more. Bruno calls it *New Year Syndrome* as many survivors complain that their muscles are significantly weaker in late December after Christmas festivities but their strength returns in January after resting. Bruno warns that transient weakness may be damaging in the long term. *When you experience transient weakness, we think you have overloaded your neurons' protein making factories and drained their reserves. After you rest your neurons' protein supply increases and you are able to use your muscles again. But every time you drain your motor neurons, we think you are doing damage that eventually causes permanent damage as the drained neurons die. Think of what happens to your car battery if you leave the headlights on every night. You get up the first morning and your battery is flat. You jump-start the battery and drive off. The next night you leave the lights on, jump-start the battery again, and drive away. But after about a week the battery will no longer hold a charge and you won't be driving anywhere ... you can replace your car's battery but you can't replace your neurons.*

Network Member's Woodwork Acclaimed

The May issue of *Australian Woodworker* published an article on the highly regarded craft and community work of Robert Guilfoyle. Robert is a wood turner and carver who produces and exhibits bowls, platters, lidded boxes and clocks. He is currently setting up a woodworking program *to teach physically and mentally disabled the skills and pleasures of his craft at a centre called Shareability Inc in Belconnen ACT.* Robert volunteered his skills at the *For You and Me Centre* two years ago. He says, *I volunteered because I get so much pleasure from turning a lump of wood into a beautiful and useful object, and I wanted to share this enjoyment with others ... My greatest achievement was helping a very disabled young woman, with cerebral palsy and limited use of one arm only, complete a lovely bowl.* He describes his need to *achieve something with my time, rather than just pass it, and to feel I am giving something back to the community.* Robert uses an electric wheelchair and has incomplete use of his arms. Consequently he must carefully plan the use of his tools to achieve the desired result. *Equipment has to be at the right height. I can't lean forward or turn my body, so I have to sit sideways to the lathe or bandsaw. Using a chainsaw to cut blanks is a real challenge.*

Polio Returns to Europe

Europe had been free of polio since 1998 and Bulgaria since 1991 but on 17 May *Associated Press* reported two cases of polio in Bulgaria. The first case was a 13-month-old Gypsy child in the Black Sea city of Burgas who developed paralysis in March. It was

diagnosed as polio three weeks later and other Gypsy children were immediately vaccinated. Despite this, in May a two-year old child living in Yambol 90 km from Burgas contracted polio and her legs and an arm became paralysed. The virus was identified as a subtype of Type 1 poliovirus that is found in northern India. WHO commented that *without constant vigilance, Europe's polio-free status and the global eradication efforts could both be in danger.*

HIV-Polio Vaccine Link Finally Debunked

I have written before about rumours that the HIV virus leapt the species barrier to humans from apes via batches of Sabin vaccine (*Newsletter* 43). These allegations were fuelled by a book, *The River: A journey back to the source of HIV and AIDS* by British journalist Edward Hooper. Hooper reported that the sites in the Congo, Rwanda and Burundi, where the first recorded cases of AIDS occurred in the 1960s were also where a million people were vaccinated against polio in 1958-59. Hooper claimed that the oral vaccine, which came from the Wistar Institute in Philadelphia, was derived from the kidney cells of chimpanzees that had SIV, a simian HIV. The Wistar Institute has always denied using chimpanzee cells. The US *Dispatch* (28/4/01) reported evidence that should destroy this *ugly theory* that has *sown doubt about medical honesty and damaged faith in vaccination.* In April the prestigious journal *Nature* published the findings of four groups of scientists in Britain, France, Sweden and the USA who tested the DNA of stored or frozen samples of Wistar vaccine. *They found no trace of HIV or its nuclear acid components, while the only simian genetic material found came from Macaque monkeys, a species quite distinct from chimpanzees (the carriers of the closest simian immunodeficiency virus (SIV) to AIDS).* Thus there is no support for Hooper's assertion that the Wistar Sabin vaccine was produced from chimpanzee cells. A recent study at Oxford University also refutes Hooper's theory. This study showed that HIV existed in humans before the mass polio vaccinations in Africa. The question about HIV's origins remains unanswered. A popular theory is that it originated in central or West Africa via a chimpanzee that bit, or was eaten by, a hunter. Such episodes may have occurred on a number of occasions. What may have caused HIV to take off epidemically could have been the use of non-sterile needles and syringes in African hospitals in the mid 20th century.

Polio Fatigue

Like me you are probably tired of people dismissing your polio-related fatigue with the words, "You're just getting old! I get tired myself these days." Such folk usually don't want to listen to research evidence disproving their beliefs but you may find some reassurance that you're not a hypochondriacal wimp from a recent study published in *Spinal Cord* (volume 39, pages 243-51). The authors, A-K Schanke and J Stanghelle, compared the fatigue levels of polio survivors in Oslo with those of the Norwegian population of similar ages. Polio survivors in all age groups experienced greater physical fatigue than their able-bodied counterparts. While 11% of Norwegians reported substantial fatigue of more than six months duration, 53% of polio survivors did so. Within the able-bodied population physical fatigue increased with age but there were no significant differences between the fatigue levels of polios aged in their forties, fifties or over 60. According to the findings physical rather than mental fatigue was the major problem for polio survivors. Male survivors were as likely to report mental fatigue as were able-bodied men of their ages. Female survivors in their forties or over 60 experienced more mental fatigue than did non-disabled women of these ages but the difference was not very great. The authors conclude that their findings do not give great support to Bruno's theory that "brain fatigue" (problems of attention and concentration) is common among polio survivors.

Disability in Childhood Books

A recent book, *Take Up Thy Bed and Walk: Death, Disability and Cure in Classic Fiction for Girls*, will give you an interesting and thought provoking trip down memory lane. Author Lois Keith became a paraplegic due to an accident in adulthood. Passing her much loved childhood books onto her daughters she noticed for the first time that *disability, illness (particularly paralysing illness) and cure are central to many of these stories ... there was hardly a girl's novel since 1850 which didn't have a character who at some crucial stage defied their guardian and fell off a swing or out of a sled, became paralysed through tipping out of a carriage or was suffering from some nameless, crippling illness ... there were only two possible ways for writers to resolve the problem of their characters' inability to walk: cure or death.* Lois' daughters know she is no poor incapable invalid and that *no wheelchair smashed by a jealous goat-herd (Heidi), magic healing place (The Secret Garden), change of personality (What Katy Did), or miracle cure in a New York hospital (Pollyanna) is going to get me up and running round again.* Lois argues that the books we read when young have the deepest influence on our lives so what were the messages we received about disability? Apart from these deeper issues it's very enjoyable to go over the plots of old favourites. *Little Women, Jane Eyre, Seven Little Australians, and Little House on the Prairie* are all there but there is no analysis of the *Anne of Green Gables* series which I suspect were the most influential books I ever read. Polio gets a mention as having great dramatic potential as a fictional device *to illustrate brave 'overcoming' of insuperable odds with medical accuracy often being ignored to allow characters to walk again.* Alan Marshall's *I can Jump Puddles* is praised for a response to wheelchairs (*not seen as an object of shame or constriction, but as exciting and liberating*) that is *unusual even today.* Rosemary Sutcliffe, who has a disability, is praised for her books, in many of which characters with disabilities fight to gain a position in society. This somewhat overpriced paperback published by The Women's Press 2001 is available at Australian bookshops for \$34.95. Gleebooks at Glebe have it. You may have to ask some bookshops to order it in for you.

Accepting things you never thought you could

American author Nancy Mairs who has MS said in an interview that everyone *imagines a boundary of suffering and loss beyond which, she or he is certain, life will no longer be worth living ... my line, far from being scored in stone, has inched across the sands of my life: at various times I could not possibly do without long walks on the beach or rambles through the woods; use a cane, a brace, a wheelchair; stop teaching; give up driving; let someone else put on or take off my underwear. One at a time ... I have taken each of those figurative steps ... I go on being, now more than ever, the woman I once thought I could never bear to be.* How true this is of the changes PPS has forced us to accept in our lives.

Dr Anna-Lisa Thoren-Jonsson of the Department of Rehabilitation Medicine, Göteborg, Sweden, has researched how PPSers manage such changes. Her article is titled *Coming to terms with the shift in one's capabilities: a study of the adaptive process in persons with poliomyelitis sequelae* (Disability and Rehabilitation, 2001, volume 23, pages 341-351). Thoren-Jonsson found that initially survivors ignored body signals such as pain and fatigue, which indicated that their physical capabilities were declining. She calls this the inattentive phase. As these survivors continued with their usual activities they entered what she named the overload phase which is characterised by increasing fatigue, pain and anxiety. *The predominant strategy in this phase was stretching the limits of physical capability, but avoidance and wishful thinking were also common ... some intensified their exercises, which led to further overloading.*

From the overload phase survivors moved through one or more of three stages. Some survivors experienced an emotional crisis, *a vicious circle of further pain and tiredness if they continued to stretch the limits of their physical capacity ... or did not see any other way of coping.* They described this period as a time of dark. Some survivors moved to a phase of withdrawal. They reduced their activities particularly leisure and social activities, often because they did not want to show their increasing disability, for example by using mobility aids, asking for help. Support from others often helped people move from the withdrawal stage, for example a relative encouraged them to seek medical help or use assistive devices. A third phase was that of gradual change. *Sometimes they realized themselves that they were tired or suffered pain in certain occupations, but mostly other persons or special incidents seemed to have called their attention to the fact that changes had to be made.*

Ultimately many survivors reached the flexible phase in which they *used a variety of strategies, a pattern which facilitated their participation in daily occupations and social life. They seemed to take the decline in their abilities into consideration in activities instead of struggling with it.* They planned and organised, set priorities, sought information, were able to ask for help, used assistive aids and no longer felt shame about their disabilities. To reach this stage of flexibility survivors needed both insight and the ability to reorganise. Insight meant recognising that disability had increased, for example as one woman said, *You can't be what you once were.* Such insight leads to anxiety says Thoren-Jonsson and *was not enough to bring about change, but it was a turning-point that started a process 'in the back of the mind'.* Reorganisation takes time. One participant in the research said: *It's something new to me to see my limitations because I've spent a whole lifetime trying to ignore the fact that I've been ill and persuading myself that I'm like everybody else. Then you have to change completely and it's not easy to turn it over and say to yourself that I can't fix that when you've always been saying I'll fix that.* Post-polio being what it is many participants returning to the overload stage when new symptoms developed or stressful events occurred in their lives. *Adaptation is a dynamic and unending process in everyday life.* For polio survivors changes associated with loss come faster and sooner than they do for most of their contemporaries. Do we get any better at coping? I suspect we do once we have initially reached the flexibility phase. No one knows how many polio survivors do not reach this stage. The participants in the research were volunteers and were likely to be coping better than average, for example no one who denies they are having problems is likely to volunteer for such research. Nor are they likely to join the Post-Polio Network!

Murder at the Sydney Opera House

Murder at the Sydney Opera House is a musical murder mystery in one act in the Agatha Christie short story tradition, written by Barbara Thompson. Barbara has very kindly offered to put on her play as a fund-raiser for the Network. We are hoping to schedule her performance for early next year, so watch this space.

Barbara has performed with many amateur musical and dramatic societies in Sydney. Her roles over the years have included Miss Marple in *Murder at the Vicarage* (Birrell Street Theatre), Miss Preen in *The Man who came to Dinner* (Genesians), Capulet in *Ring Round the Moon* (Phoenix Theatre), Queenie in *Showboat* (Rockdale Opera), Mrs Primrose in *On the 20th Century* (Regals Musical Society), and Fraulein Schneider in *Cabaret* (Hornsby Musical Society).

And the plot of Barbara's play? A group of friends go to an opera at the Sydney Opera House and one of the guests dies after drinking poisoned champagne. Aunt Jane is a murder mystery enthusiast and fancies she is just as good as Miss Marple at solving life's little mysteries, but can she solve a real murder?

Support Group News

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In preparing for the Annual Report I have had responses from many of our Support Group Convenors and share here with you some of their news. Our Support Groups are an integral part of our Post-Polio Network and I take this opportunity to express my sincere thanks to them for their effort and commitment to our members.

Brian Toby at **Campbelltown** is one of our original convenors and conducts a telephone support group for members in the outer southern area of the city. He is in regular contact with a number of members and is keen to hear from other interested members. Brian can be contacted on 02 9618 2279.

The **Northside** group continues to meet on the first Saturday of each even month and are sometimes joined by members from other support groups. Convenor **Ruth Wyatt** tells me that they have a fun time together and recently enjoyed a "Christmas in July" gathering hosted by Gwen Hayes where they had a wonderful lunch.

One of our newer groups at **Orange** is convened by **Susie Simmons** who has approximately a dozen members residing in her area. Susie was recently instrumental in assisting a member from Condobolin to contact a health professional who could provide some assistance.

Our **Coffs Harbour** convenor, **Ken Dodd**, highlights several factors which are beginning to impact on many groups. These factors are age, increasing disability and a lessened ability to travel. Despite these handicaps a small number of members regularly make the effort to attend meetings and provide mutual support.

I believe, like Ken, that many of our groups will depend more on telephone contact interspersed with several social events each year as members become less mobile.

The **Shoalhaven** group, energetically led by **Dorothy Schünmann**, continues to meet at the Nowra Library meeting room on the third Friday of each month and are still gaining new members. They enjoy a Christmas luncheon and end of year barbecue. Dorothy is hoping that they will be able to have a table at the Nowra Fair Complex during Polio Awareness Week.

In speaking with **Barbara Tunnington** who is convenor of the **Central Coast** Support Group I know that they meet regularly at the Kincumber Multi Purpose Centre as well as providing telephone support to members who cannot attend meetings. I am rather keen to explore a suggestion that Barbara has made of having a "Reaching Out" session in larger population areas where we provide information on benefits that membership can provide.

The **Inner West** Support Group is a well established group of members who have become close friends over an extended period of time. Convenor, **Claire Dawson**, who normally hosts the group at her house, tells me that they very much look forward to their meetings but like many of us some are being hampered by mobility and transport.

Several new members have recently joined the **Hornsby** Support Group which is very encouraging for **Kerry Jenkin** who has convened the group for the past four years. Kerry provides both telephone support as well as organising social gatherings. It is very pleasing to hear that Kerry is gaining much satisfaction from her position on the Hornsby Shire Council Access Committee and would encourage other members to take a more active role on decision making bodies in their local community.

Gregg Kirkwood who is our convenor in the **Dubbo** area conducts a telephone support service but is very keen to hear from members in the vicinity who may be willing to meet. Gregg may be contacted after 6:00 pm on (02) 6884 9108.

The **ACT** group based at Canberra is one of our largest and most active groups. Convenor, **Brian Wilson** has provided me with a very comprehensive report of activities. Brian and several colleagues have addressed a Rotary meeting and have had a reciprocal visit from Rotarians at a well attended meeting. Brian has also been interviewed on radio.

In the north of the state **Rosalie Kennedy** conducts the **Northern Rivers** Support Group which meets every second month at Lismore and Ballina. There are generally six to ten members in attendance at meetings whilst telephone support is also provided.

It was good to hear from one of our oldest convenors, **Jean Robinson**, who very ably runs a Support Group at **Young**. This lady has an indomitable spirit and wonderful attitude to life. Jean tells me that they will meet again when the weather is a little warmer!

In the Illawarra region, **Dorothy Robinson**, convenes the **Wollongong** Support Group where they have 8 to 12 members in attendance at meetings. A guest speaker, Dr Wilbur Chan, generated much interest and he is keen to return for another visit. There is also a possibility that a Polio Clinic will be conducted at Port Kembla Hospital.

After struggling for numbers for some time the **Lower Blue Mountains** Support Group now has half a dozen members who regularly attend meetings at the Kingswood Community Health Centre on the third Monday of each month. Convenor, **Bernie O'Grady**, reports that they share information about their interests and enjoy fun and laughter at luncheons. It was great to hear that three of them are going to the heated pool at the Blacktown Aquatic Centre each week for gentle exercise.

The **Northern Inland** Support Group are very fortunate to have **Laurie Seymour** who is editing a very enjoyable publication, "THE LINK" for members in the north west of the state. Unfortunately the "Round Robin" means of communication is beginning to wane. If members have either of the books could they please keep them moving or alternatively make a contribution through "THE LINK". I know that Laurie would love to hear from you.

Our largest Support Group, the **Hunter Area** group, continues to have very good attendance at its meetings which are held each on the first Wednesday of each month at the Toronto Workers Club. Meetings feature guest speakers, members contributions, open forums and sharing sessions. Convenor, **Wendy Chaff**, also prepares a very informative newsletter which is distributed to over 60 people.

In **Grafton**, Convenor **Susan Stewart** continues to operate a telephone Support Group where she is in contact with members and is a reference person in the community for the Network.

I have just received a very newsy letter from **Marion Wardman** who is in the far west of the state at **Nyngan** where she keeps in regular contact with Ruth Williamson. Although doing it tough Marion has been busy distributing posters for Polio Awareness Week and talking to the local paper. This epitomises the spirit of our Convenors as they go about the business of promoting the Network.

Recently we held a very successful inaugural meeting for members in the **Eastern Suburbs** area. In addition to half a dozen members being present, there were expressions of interest from another dozen members. A further meeting is being planned for early December where we hope to establish a regular meeting venue and decide frequency of meetings.

I am looking forward to seeing many Convenors at our Mini-Conference on 16 December where we will hold a special Convenors' workshop as part of the activities for the day. To date eleven Convenors are attending. A number of others were very keen to come but for family or personal reasons are unable to be there. We will miss you.

For those Convenors who won't be with us on 16 December, I wish you and your families a peaceful, and hopefully restful, Christmas. I will be in touch in the New Year to give everyone feedback from the Convenors' workshop.