

POST - POLIO NETWORK (NSW) INC.

NETWORK NEWS

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President's Corner

Gillian Thomas

Welcome to the last *Network News* for 2002 which has plenty to keep you informed and entertained over the Christmas holidays. Members will also find the Network's 2001/2002 Annual Report and Financial Statements enclosed with this issue, together with our new Medical Alert Card.

At the Network's fourteenth Annual General Meeting held on 30 November the following members were elected to the Management Committee:

Gillian Thomas	<i>President</i>	George Laszuk
Merle Thompson	<i>Vice-President</i>	Bing Mak
Janet Malone	<i>Secretary</i>	Peter Preneas
Bob Tonazzi	<i>Treasurer</i>	Alice Smart
Anne Buchanan		John Ward
Ann-Mason Furmage		Mary Westbrook

Elizabeth Joyner did not re-stand for the Committee and we thank her for the time she has given the Committee in the previous two years. Elizabeth's expertise won't be lost to us, however, because she will continue to assist in the development of the *Professional Resource Register*. While not elected to the Management Committee, Neil von Schill will continue in the vital role of Support Group Co-ordinator and advisor on regional issues.

At the conclusion of the AGM, Merle Thompson officially launched our colourful new *Medical Alert* card. Made of laminated plastic and in a handy wallet size, the card succinctly describes the late effects of polio and the implications they may have for polio survivors. Your free copy is enclosed (attached to the back of the address sheet). If you would like a further copy, a stamped self-addressed envelope (or a small donation if you require a number) would be appreciated.

Following the lunch break, our guest speaker from Melbourne, Dr Keith Hill, gave a very interesting presentation on balance, including falls and how we might prevent them. Roving reporter Wendy Chaff has offered to write up his talk for the benefit of members unable to attend, and her report will appear in an upcoming issue of *Network News*. Copies of the slides used in the presentation are available on request, and the talk was also tape-recorded. Upon his return home, I received the following note from Dr Hill. "*Congratulations on a very successful AGM on Saturday. All the hard work which goes on behind the scenes is often not reflected at these events, however it seems from an outsider's perspective that the work done by the NSW Network is extremely valuable for your members, as well as the broader range of stakeholders such as health professionals.*"

Finally, it is with great sadness that we report the passing of John Westbrook after a lengthy illness. John was a quiet man who was liked and respected by all who knew him. After a private funeral, several Committee Members represented the Network at a moving memorial service which was a fitting tribute to a gentle man. Our sympathy and thoughts go out to Mary and her family at this time.

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The Power of Pilates

Vicki Negus, BSc Physiotherapy, Pilates Practitioner

Sonja Schulze, BSc(Hons) Physiotherapy, Pilates Practitioner

You may have seen increasing mention of “Pilates” in the media this year. Member Dr Rachelle Andgel recently forwarded me a copy of an assessment of her post-polio problems both before and after Pilates-based rehabilitation sessions. Rachelle wrote that she had received great benefit from Pilates therapy and she wished to share her positive experience with other members through Network News. Accordingly, I wrote to the Pilates practitioners she had worked with, Vicki Negus and Sonja Schulze from Balancé Physiotherapy & Pilates Clinic, and asked whether they could refer me to a paper describing this rehabilitation method. Vicki and Sonja kindly put together the following article for the benefit of members.

I draw your attention to the advice in the article to ensure that you have a thorough assessment resulting in individually-tailored exercises before you embark on a Pilates-based rehabilitation program.

If you would like more information please contact Vicki or Sonja at their St Leonards Clinic on (02) 9906 6911, or by email <sonschulze@ozemail.com.au>.

History of the Pilates Method

Joseph Pilates (1880 – 1967)

- Born 1880, near Dusseldorf in Germany.
- Sickly child – dedicated his life to creating an ideal conditioning program. Experimented with Eastern and Western philosophies.
- Left Germany in 1912 to train as a professional boxer in England. Taught self defence to Scotland Yard detectives
- Outbreak of World War 1, interned as an enemy alien in Lancaster, then transferred to the Isle of Man.
- Used his camp time to evolve his conditioning theories.
- Experimented with springs as resistance aids while working as a nurse in the camp hospitals. Led to his creation of the “universal reformer”.
- Returned to Germany after the war, trained the Hamburg Police Force.
- Immigrated to the USA, when instructed to train the New German Army.
- Opened first exercise studio in New York in 1926, calling his method Contrology. His first clients were dancers, who found the Method complemented the demands of their dance training, while also helping with injury prevention.
- The Pilates Method has become popular since the 1980s in the arenas of fitness and rehabilitation.
- Since the 1990s much research has been done by physiotherapists in the area of spinal stabilisation. The Pilates Method has recently been applied to the treatment and prevention of low back pain, as well as other injuries, in conjunction with these new research findings.

The Principles of Pilates

Alignment

“Each muscle may co-operatively and loyally aid in the uniform development of all our muscles” J Pilates

- No body part functions in isolation
- Picture a building with uneven foundations
- External stability as well as internal functioning is affected
- General health is affected by posture – musculoskeletal, myofascial, neural, vascular, lymphatic and visceral function → gravitational strain pathophysiology⁽⁴⁾

Static Posture – position of motionless body

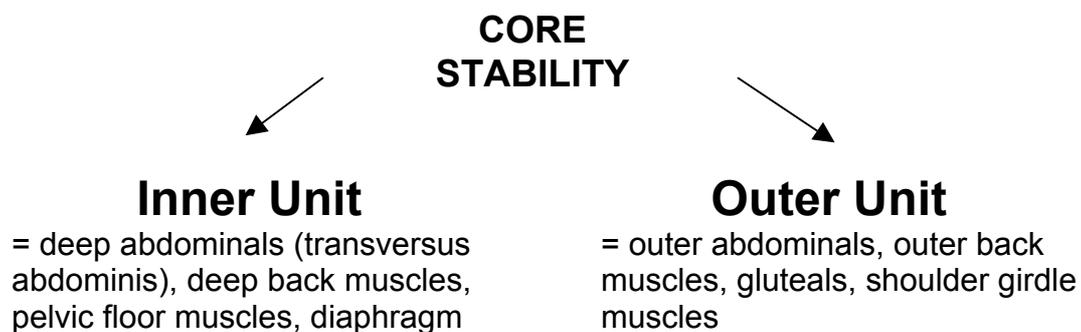
Dynamic Posture – maintenance of alignment with motion

- Static posture does not automatically translate to dynamic posture
- Depends on neuro-motor memory of past experiences of the same movement

Pilates encourages optimal static and dynamic posture through feed forward adjustments. Clients repeatedly perform various functional movements with correct muscle sequencing and patterning. In time, the conscious control of correct posture in different movement sequences becomes the natural automatic process of functioning.

Centering

Pilates described the lumbar spine and pelvis as the “power house” of the body.



Key to Success of Pilates

- Emphasis on stability of neutral spine, scapulae and pelvis in all exercise sequences.
- Submaximal resistance to ensure adequate control.
- Co-contraction encouraged as opposed to emphasis on prime mover.

Breathing

“To breathe correctly you must completely exhale and inhale, always trying to “squeeze” every atom of impure air from your lungs in much the same manner that you would wring every drop of water from a wet cloth” – J Pilates

Current Research

EMG activity in the diaphragm coincides with that of transversus abdominis.

- Diaphragm - primary muscle of respiration
- shares attachment with transversus abdominis
- Pilates encourages posterior lateral basal breathing
Transversus abdominis remains “switched on”
Posterior lateral ribcage expands

Benefits

- maintains mobility of ribcage and hence thoracic spine
- improves respiratory function through increased lung capacity
- discourages use of accessory muscles in neck
- ensures spinal stability is maintained
- prevents increased pressure on the pelvic floor muscles (caused by holding the breath)

General Rule – Breathe out on the effort

Concentration

“Concentrate on the correct movements each time you exercise, lest you do them improperly and thus lose all the vital benefits of their value.” – J Pilates

Co-ordination

“Correctly executed and mastered to the point of subconscious reaction, these exercises will reflect grace and balance in your routine activities.” – J Pilates

Flowing Movement

“Contrology is designed to give you suppleness, natural grace and skill that will be unmistakably reflected in (all you do).” – J Pilates

Precision

“Ideally our muscles should obey our will. Reasonably, our will should not be dominated by the reflex actions of our muscles.” – J Pilates

Relaxation

“Not too much, not too little.” – J Pilates

Application of Pilates in Post-Polio Syndrome

There has been no research into the effects of a Pilates-based rehabilitation program on management of post-polio syndrome. However, as the Pilates Method involves low-impact, non-fatiguing exercises, it can be an appropriate form of exercise for people with the syndrome, who are experiencing new muscle weakness and fatigue.

The exercises, when performed with adequate supervision, focus on the maintenance of correct alignment and postural control, therefore the Method is also safe and unlikely to

cause injury. Some, even long-term, effects of the syndrome can be improved with an individually tailored program. The most significant changes will be seen in areas resulting from 'disuse' weakness, rather than from the original poliomyelitis.

Several studies have found benefits of low-impact exercise programs in post-polio syndrome. Ernstoff et al (1996) demonstrated that a program of low-resistance exercises for all major muscle groups, performed twice-weekly for six months, resulted in significantly increased strength in certain muscle groups. No injuries or complications were experienced, and only one subject complained of muscle fatigue.

People with post-polio syndrome should seek out Pilates Studios which perform a thorough assessment and tailor a specific program for each client. Pilates Studios use a variety of special equipment incorporating light spring-based resistance. There is no emphasis on heavy weights. The aim is to use the light resistance of springs and body weight to challenge the major postural muscle groups, which are commonly weakened in post-polio syndrome. It should be noted that the Pilates mat-work classes run in gyms are fitness-based, not rehabilitation-based. Therefore the exercises demonstrated are not individually-tailored, are not usually sufficiently supervised and corrected, and may be too difficult or inappropriate for a client with post-polio syndrome.

It is beneficial to seek out a Pilates Studio affiliated with a physiotherapist, as physiotherapists are trained in the assessment and treatment of neurological conditions. Physiotherapists can also advise on the use of non-Pilates equipment, such as therapy balls and wobble boards, and may incorporate these into a Pilates-based program. Physiotherapists can also take into consideration individual differences in exercise tolerance and physical ability.

The aim of using the Pilates Method in post-polio syndrome is to improve mobility, strength, balance and functional ability. This can enable people with post-polio symptoms to return to a greater level of function and enjoyment in exercise, work, hobbies and daily activities.

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Doing All Right:

successful ageing concepts and implications for action in sustaining the health of an emerging population of women with long-term disabilities

This thought-provoking paper by Victorian member Margaret Cooper AM was presented at the 4th Australian Women's Health Network Conference "Politics, Action & Renewal", Adelaide, February 2001, and is reprinted here with the Margaret's kind permission.

Abstract

Gender issues affecting ageing women are insufficiently studied (Heycox 1997). Women who are ageing with severe disabilities sustained earlier in life have been identified as needing a specialised model of assessment to inform adequate health management (Cooper & Temby 1998). Zarb (1996) proposed that people with disabilities would react to events of ageing similarly to the way they had reacted to the onset of disability. A pilot project was undertaken to explore the complexity of the ageing experience for women with long-term major disabilities, and to discern any common adaptive strategies used by these women to age successfully. Findings indicated the women remained socially active despite increasing disability. Their histories of adaptive abilities were reminiscent of the successful ageing criteria postulated by Baltes & Baltes (1990). Improved understanding of this group of women will indicate trends useful for informing further areas for research, health care and other forms of service provision for ageing women with long-term disabilities.

Introduction

A woman who incurs a permanent impairment has to adapt to her new altered physical or sensory self, to her community's perception of disability, and consequent reinterpretation of female identity by her social networks. This adaptation may be a precursor for how she will deal with the experience of ageing, which adds another dimension to her life. This paper explores the experiences of fourteen women who have been mobility impaired for many years, and who are now ageing. These women have all had to face major adaptational events. Their experience and current strategies for self care are explored for evidence of any relationship to the concept of successful ageing.

The word "long-term" is used to define the temporal context of the women surveyed in this project. All have been impaired for decades. Their lives have been affected as a consequence of community perceptions of their identities as disabled.

Successful ageing

Successful ageing has been defined many ways. The term can mean maintaining health without any loss of function (Rowe & Kahn 1987), and may include high cognitive scores, self-reported good health and living in the community (Jorm et al 1998). However this definition denies the reality of the social construction of ageing and the need to incorporate body frailties associated with increasing age.

Baltes & Baltes (1990:5) positively associate successful ageing with seven criteria: length of life, biological health, mental health, cognitive efficacy, social competence and productivity, personal control and life satisfaction. Baltes & Baltes suggested that given the wide variation in and between the variables involved in the study of successful ageing, any prediction regarding an individual, had to be relevant to that person's ability to meet their own goals given the norms in their own psychological and social realms. The ability to meet goals involves three key elements determined by the person and surrounding systems,

selection of goals, compensation or use of alternate means to reach a goal, and *optimisation* or making the most of available functions (Baltes & Baltes 1990).

Ageing with long-term disabilities

People with severe disabilities are ageing in increasing numbers (Ansello 1988, Crewe 1990, Ansello & Eustis 1992, Trieschmann 1992). Australians ageing with disabilities are increasing (Wen, Madden & Fortune 2000). It is not known whether the type of impairment affects the individual's progress towards successful ageing. Successful ageing for this population needs definition to inform appropriate approaches to health care.

Baltes and Baltes model is useful when looking at the ageing of people with disabilities, as it is a process-oriented approach (Baltes and Carstensen 1996), and enables the concept of successful ageing for this population to be measured according to personal goal achievement rather than failing some arbitrary construct.

Zarb (1996) has postulated a disability/ageing career, which demonstrates the relationship of past and present events in the lives of people with disabilities. Experience of disability onset, events of ageing, and resource availability can be combined to give a picture of the individual's quality of life. Drake (1998) reported on a study on two groups; people who were ageing with and without disabilities. The concerns of both groups coincided to a considerable extent, a common concern being *"their abilities to participate in the ebb and flow of everyday life"* (p. 166).

The social construct of disability

Learning to live with impairment is a major adaptational event and many emotions are expressed by the individual. The emotions experienced are heightened by the significance of a threat to the person's ability to proceed with life choices, as emotions *'depend on the values, goals and beliefs to which we are committed and which are important in our lives'* (Lazarus 1991: 467). The more substantial the impairment, the more important the individual's social and material environment will become to the realisation or otherwise, of personal goals. Anger, despair, jealousy and other emotions all surface as the newly impaired person reacts to the magnitude of her impairment. Sometimes emotional reactions by patients in rehabilitation are blocked by medication or staff attitudes (Morris 1995) which can delay working through of issues. Adaptational tasks include coming to terms with loss of function, changes to appearance and renegotiating social and intimate relationships (Seymour 1998), redeveloping physical independence and care systems (Morris 1995), and dealing with prejudice against people with disabilities (Morris 1991). Women with disabilities face additional negative perceptions (Cooper & La Fontaine 2000).

Coping is defined by Lazarus as consisting of *"cognitive and behavioural efforts to manage specific external or internal demands (and conflicts between them) that are appraised as taxing or exceeding the resources of the person"* (p. 112). For example a newly impaired person copes with mobility issues by learning to manage assistive technology such as wheelchairs, white canes, wheelchair accessible cabs, and audio/tactile cues at public transport points. Disability onset may also mean learning to work with personal care workers or domiciliary therapists. Changes in the person's control over social roles may occur such as an altered relationship, transfer to alternative employment, and thus further adaptive behaviour is required.

The experience of people with disabilities is that disability is a social construct, and barriers to full participation are targeted for change. The aim of a social definition of disability was to move away from medical concepts (Abberley 1987). Australian activists brought the social model definition into Australia in 1982 (Cooper 1999). It read: *"Disability is the loss*

or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers.” (Cited in Cooper & Strochnetter 1990:84)

Adaptation and women with disabilities

Women with long-term disabilities may face additional gendered obstacles to ageing successfully (Morris 1991, Zarb 1996, Temby & Cooper 1998). An ability to adapt to changed circumstances is another indicator of successful aging which “*is but one expression of a generic transactional process, namely adaptive competence ... which is a generalised capacity to respond with resilience, to challenges arising from one’s body, mind, and environment* (Featherman, Smith and Peterson, 1990, p. 53).

As a woman ages she has to adapt to many changes such as menopause, children leaving home, perhaps the loss of secure employment, and the onset of ageing which may bring a susceptibility to such conditions as osteoporosis, or reduced visual and aural acuity. However many researchers have found ageing people have potential to improve their health and psychological status (Baltes & Carstensen (1996).

Exploratory study

The purpose of this study was to explore the meaning and experiences of ageing for women who had lived with disability for a long time and were now facing the ageing process. Fourteen women volunteered by answering flyer advertisements on two disability related internet information lists and in the Victorian Paraplegic and Quadriplegic Association newsletter.

A structured interview was conducted with each individual, incorporating a questionnaire designed to discern historical information about the primary disability, initial and long-term adaptive strategies, and current social status information. A *Quality Of Life Questionnaire* was also used to assist in the assessment of the individual’s satisfaction with their immediate status.

Results

Apart from broad descriptive data, the results are organised under Baltes and Baltes variables of successful ageing.

Thirteen women owned their own homes or units outright or shared ownership with a current partner. Two had bought units within retirement villages, one paid rental to a retirement complex.

Four women lived with their spouses, one was divorced, two widowed, and seven had lived single lives.

Only one participant lived on wages or salary. Three women were financially supported by their husbands. One of these contributed to her partner’s business, the other two earned some money by occasional casual work. One woman lived on superannuation, while another had partial superannuation. The remaining eight received Disability or Age pensions. Older women in this study had less financial security because education and employment opportunities had been less available for them. Most of their employment was undertaken during a time where superannuation for women was unavailable or consisted only of provident fund contributions.

Participants all had a major adaptational change caused by the onset of impairment and disability in late adolescence or adulthood. Four women who incurred impairment as

children did accept they had some degree of permanent impairment but did not perceive themselves as disabled until secondary effects occurred in their fourth decade of life. Two women were paraplegic as a result of spinal cord injury or transverse myelitis. Twelve women had a degree of paralysis from polio. The latter group all had an increase in symptoms consistent with their self-defined post-polio syndrome.

Length of life

The age span of the participants was between fifty-five to eighty-eight years, most being in their sixth decade.

Cognitive efficacy

This factor was explored by the women's self-reports of their education, paid and unpaid employment histories. The participants had varying degrees of education from eighteen months primary school only to university level. Participants had varied employment from printer's assistant to tailoress to nurse educator. Many had held more than one job.

Social competence and productivity

Current involvement with voluntary work by participants was taken as one measure of this variable. Eleven participants remained actively employed by unpaid voluntary work, once their paid work had ceased. Two women were predominantly involved with their extended families. One of the latter had become principal carer for a spouse with recent moderate cognitive impairment. One woman kept a relatively small network as compared to the others. The women updated their skills by committee participation, attending social groups, reading newsletters, networking with friends and acquaintances, and six had undertaken short courses within the last year.

Biological health

Participants all had mobility impairments caused by paraplegia or polio. Five used wheelchairs fulltime and three more used wheelchairs or scooters outside the home. Five used personal care attendants regularly to assist with activities of daily living.

Health issues were self-reported by some women. Some were able to relate these directly to their impairment. Their concerns included increasing weakness, fatigue, and non-specific pain. Health matters perceived as related to ageing, or ageing with female biology included osteoporosis, auditory loss, cardiac problems and cancers of the breast. Women who reported visual loss and leg ulcers were confused about whether their issues related to initial impairment, female biology or ageing.

Mental health

This criterion was explored in relation to each participant's reported coping strategy at the time of the impairment and their reported coping with ageing. No clear pattern of repeated adaptational strategies emerged. Women who had been impaired during childhood had clear dramatic memories of their traumas, and their reports were evocative of unresolved feelings. The onset of new symptoms in middle age elicited strong emotional responses from this subgroup. Most participants reported attention and memory difficulties. One participant reported a history of depression requiring current medication.

Personal control

Participants rated control over their own lives as extremely important. The achievement of personal goals was very important to each. When discussing their situations each woman

stressed how much she could do for herself, however each was aware of their own immediate physical stress in being independent. All were aware of relevant community services but most used only home help or a handyman/gardener service.

The *Quality of Life Scale* was used to elicit participants' perceptions. A mean score of 24.5 indicated a high degree of satisfaction with life. A similar high score of 28.7 reflected the value attached by the women to their independence. A slightly lower score of 23.3 was given to social belonging and community integration.

Discussion

This small pilot study has shown women ageing with long-term disabilities who have learned to live with major physical changes from the onset of impairment. Application of successful ageing concepts (Baltes & Baltes 1990) is possible.

There is little research on the longevity of people with physical disabilities (Wen et al 2000). Their biological health may be considered compromised. All have experienced new impairment and health conditions, cardiac problems and osteoporosis for example, which may be due to the ageing process. Alternatively some of the women may have experienced secondary complications of their primary impairment, such as post-polio syndrome (Cashman 1987) or late effects of spinal cord injury (Whiteneck et al 1992).

Their mental health and cognitive abilities appear unimpaired. One woman had medication for depression. Although attention and memory difficulties were reported by all participants, this may be within normal limits for ageing women. Recent work by Hazendonk (2000) found there was little neuropsychological evidence to support this contention of memory loss by people who had polio, and suggested depression may be an alternative explanation. Worth considering also is the exposure of these women to reports of memory loss in disability newsletters.

Social competence and productivity are positive findings for this group. The number of involvements in committees, and social groups was indicative of successful social interactions.

Personal control was a value strongly held by all women. While this is a successful ageing criterion, there are negative aspects. Some participants appeared to be denying their need for assistive services, in an attempt to minimise intrusion by helpers. The title of this paper was derived from a common comment of participants. Denial of need may become a maladaptive behaviour if the individual suffers worsening of a condition as a result. In this small study there appeared to be a trend which indicated women, who had perceived major negative aspects to the way their initial impairment was treated, were less likely to seek help for health issues in later life. Zarb (1996) suggested behaviour learned during the onset of disability might recur during ageing events.

Life satisfaction was expressed by all participants and all have retained personal goals and objectives.

Gender discrimination issues were expressed by all women who had been employed. Three women felt they experienced disability discrimination by being unable to access screening facilities for breast and bowel cancer. The social activity of older women (Heycox 1997, Day 1990) and women ageing with disabilities (Armstrong 1991) may be underestimated. It would be interesting to research whether males are as socially active.

To summarise, Baltes and Baltes 1990 successful ageing criteria are useful in the evaluation of the status and experience of women ageing with long-term disabilities. These criteria might be used to inform assessment models and practice developments for health maintenance of this growing population.

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Program of Appliances for Disabled People (PADP)

In Newsletter Issue 48, February 2001, we reported that a new PADP Policy had come into effect on 1 January 2001. Almost two years down the track we thought it timely to give you an update on how the new Policy and related procedures are working. As so many Network members use a range of appliances it is important for you to be aware of how to access the Program and what types of appliances are available.

The NSW PADP Advisory Committee meets every quarter, and the Network is represented by Gillian. Gillian also participates in the caucus of disability organisations which meets before every Advisory Committee meeting to discuss emerging issues.

To be eligible for PADP assistance you have to be a permanent resident in NSW with a long-term or permanent disability and not be eligible for equipment under other government programs, from compensation and not be eligible for equipment from hospital loan schemes.

While this means that virtually all our members may be eligible there are priorities depending on income. Band 1 includes people in receipt of Pensioner Benefit or Health Care cards, rising to band 4 for those with incomes above \$39,941 single or \$67,899 for a couple or family. Applicants in Bands 1-3 have priority. People who receive assistance are required to make one payment per year of \$100 towards the cost of equipment received and some higher income earners may be required to pay up to 20% of the costs.

A significant change is that a new Equipment List is in the final approval stage and will soon be launched. The List will no longer list specific items but rather give generic categories. For example, a section called *Orthoses and Footwear* describes orthoses as “aids that support the function of any part of the body by their external application”. Items included under this category are orthoses and footwear to support a long term or permanent disability, depth shoes, surgical footwear and callipers. Up to two pairs of shoes can be supplied each year – an increase from one pair and the Network’s submissions were partly responsible for this change. Polio survivors might require items from several categories such as mobility aids, toileting and showering aids, and transfer aids.

This year’s budget was \$15.7m plus \$2.5m specifically for supply of oxygen. It is hoped that next year’s budget will see a significant increase. The Department of Health needs to be aware of the extent of the need for equipment. Many people may not apply because of previous rejections and known or believed waiting lists but **it is only by applying that the extent of the need can be quantified**. Don’t be put off from applying because you need a high-cost item – applications are prioritised with regard to how supply will assist in a person’s participation in the community.

It is very important that you let us know if you have any problems accessing the PADP scheme or receiving equipment. We will take up any systemic issues you raise with the Advisory Committee or, if indicated, directly with the Department of Health.

David Bodian Memorial Awards Polio Survivors' Unsung Heroes

David Bodian, “unsung hero” of polio and Post-Polio Sequelae, discovered that there are three polioviruses. He also uncovered the path the poliovirus followed - from intestines into blood and ultimately into neurons - discoveries that made a polio vaccine possible. What isn't known is that Bodian spent nearly every evening during the early 1950s on the phone with Jonas Salk, helping him develop the first polio vaccine.

Bodian's research also laid the foundation for understanding how poliovirus damage set the stage for PPS. He found that 96 percent of motor neurons were damaged by the poliovirus but that at least 60 percent had to be killed before muscles showed any weakness, and that the poliovirus damaged the brain stem whether or not it damaged the spinal cord, explaining why “brain fatigue” is the most common PPS symptom.

To honour his contributions, the International Post-Polio Task Force, headed by Dr Richard Bruno, has presented the David Bodian Memorial Award to recognize other unsung heroes of PPS. Internationally, ten people were honoured on behalf of the world's 20 million polio survivors.

In America, the Awards were presented to:

- Senator **Bill Bradley**, actor **David Morse** and Congressman **Steven Rothman** – all of whom were instrumental in ensuring that guidelines for polio survivors' social security disability income were not only released but followed;
- polio survivor **Debra Refson** – who conceived of The Post-Polio Letter, a one-page description of PPS to educate polio survivors and doctors throughout the world; and
- polio survivors **Mia and Thaddeus Farrow** – who agreed to spearhead the PPS education effort by co-sponsoring The Post-Polio Letter campaign and asking UNICEF to distribute PPS information as part of its polio vaccination program.

Elsewhere in the world, the following polio survivor activists were honoured:

- **Hilary Hallam** and **Chris Salter**. In 1997 Hilary created the *Lincolnshire Post-Polio Network* to distribute PPS information and lobby for acceptance of PPS and treatment for polio survivors in England. Chris joined LPPN and created the most comprehensive repository for PPS information on the Internet.
- **Gillian Thomas** was one of the founders of the *Post-Polio Network (NSW) Inc* in Australia in 1989. Thirteen years later as the Network's current President and long-standing Newsletter Editor, she is still spending many hours each week working for the Network and for polio survivors. She keenly promotes fellowship, interaction and information-sharing between polio survivors throughout the region by her leading role with Polio Australasia.
- **Cilla Webster** founded South Africa's *Post-Polio Network SA*. She and her husband have funded her newsletter and provided Internet and telephone outreach to Africans, primarily using their own small disability pensions. Post-Polio Network SA has been the only voice in Africa disseminating information about PPS to health professionals and polio survivors and lobbying African governments to accept PPS and to pay for treatment.

The presentation ceremony and reception was held in America at the Englewood Hospital and Medical Center on 27 September 2002. Although none of the international recipients was able to attend in person, their acceptance speeches were forwarded to Dr Bruno to be read on the day. We thought you would also be interested to read them.

Hilary Hallam - England



**Founder and Chair
Lincolnshire Post-Polio Network**

www.lincolnshirepostpolio.org.uk

I would like to express my thanks to all who were involved in my becoming a recipient of the David Bodian Memorial Award. It is a great honour.

Like Cilla Webster in South Africa, I founded our organisation after seven years of frustration following a fall, of having increasingly medically recorded yet unexplained symptoms. I thought polio was part of my past and now I learned there was a further stage of this condition. I never thought to remind the health professionals examining me that I had had polio.

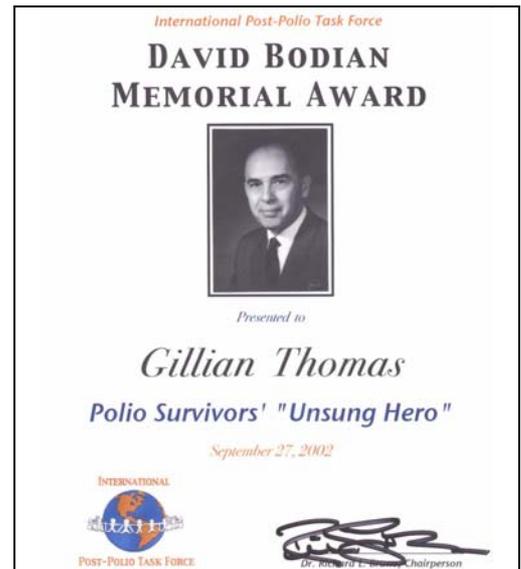
A few months later I was privileged to meet UK Emeritus Professor WJW Sharrard, like David Bodian world-renowned for his work on polio, and he explained. Polio does not go away; there is a marvellous recovery system without which we would have remained at our worst, and that most doctors working at the time of the major outbreaks knew that the level of recovery would not last all our lifetime.

My relief at finding there was a possible cause for my problems was short-lived when I found that there were hardly any UK specialists with good knowledge of polio and its late effects. In fact most of those I met told me that they were unaware the condition existed. My searches for British Medical Articles produced little compared with other some other countries. I later learned that Medical Colleges who did have polio on their curriculum allocated 15 minutes but rarely were its late effects mentioned.

I have to thank Tom Walter for putting me on the right track after my first day on the Internet when I printed off enough information to wallpaper my house three times over! At his suggestion I joined the St Johns Polio Email List and met many Polio Survivors worldwide including Chris Salter who single-handedly has produced our WebSite. I was now part of a wonderful Family of Polio Survivors, who continue to search for information, attend Conferences and other PPS and allied meetings, form Support Groups, produce informative WebSites, Newsletters and more.

It is the worldwide sharing of experiences amongst Polio Survivors and PPS Specialists, time that is given so freely, that is speeding up the spread of information on the problems that polio survivors can get in later life. Together we should now ensure that our condition and its problems are included on the curriculum of all medical colleges worldwide.

Gillian Thomas – Australia



I am delighted to have been selected to receive one of the inaugural David Bodian Memorial Awards. I am particularly proud that an Australian should be so honoured.

In Australia in 1989 when I helped found the Post-Polio Network (NSW) Inc very little was known about the late effects of polio. Any publicity resulted in hundreds of people contacting the Network, and they were very concerned about their future. Today, thanks to the efforts of the Network's dedicated volunteers, Australian polio survivors, their families, and a wide range of health professionals have an unequalled resource to help them understand and manage polio's late effects.

I am proud to have been a part of the Network since its inception, and to have helped guide its growth into Australia's largest and strongest support group of, and for, polio survivors. To now receive international recognition is a very satisfying acknowledgement of my efforts and of the importance of the Network to Australia's polio survivors.

In recent years polio survivors have benefited greatly not only from the establishment of support groups, but from ready access to the wealth of information on the internet. Through emails we are now able to tap into each other's combined knowledge and experience and receive almost instant responses. As Editor of the Network's Newsletter I have been privileged to have the opportunity to link up with polio survivors, support groups and researchers across the world, and to be able to bring relevant, authoritative and up-to-date information to Australia's polio survivors. Today more than ever we who are experiencing polio's late effects are able to do our own research into management techniques and treatments and to work in partnership with our doctors to maintain and improve our quality of life.

I would like to thank Dr Richard Bruno for inaugurating this Award to recognise the efforts of those who have worked tirelessly to help polio survivors world-wide fight their new polio battle. I also extend my congratulations to the other Bodian Memorial Award recipients who have achieved so much, often against a background of disinterest or, worse, disbelief. In particular, I am pleased to number Hilary, Chris and Cilla amongst my friends although we have never met in person.

Cilla Webster – South Africa



Founder

Post-Polio Network SA

Thank you to the Chairman, Dr Bruno, and the committee of the Post-Polio Task Force for choosing me as a recipient of the David Bodian Memorial Award. It is indeed a great honour.

The South African group was born because of the pain and frustration that I went through before finding out that I had Post-Polio Syndrome. It surprised me that Post-Polio Syndrome existed, but it surprised me even more that there was a general lack of knowledge in South Africa on the sequel to a virus that had crippled thousands of children and adults some forty years before. I felt it my duty to change this as best I could.

I was fortunate to meet Chris Salter and Hilary Hallam on the Internet and they were tremendous in helping me in the beginning and I congratulate them on being recipients of this Award as well, they are very deserving of it.

In my hunger for knowledge, I came across the information of Dr Richard Bruno who willingly gave me permission to reprint his documents in my newsletters, which proves to be invaluable to my work and my life.

I have also been assisted with information from Dr Henry Holland, Mary Atwood and Steve McMahan for which I am grateful.

It is a privilege working with polio survivors as I do, and I look forward to spending the rest of my life giving to the South African and African polio survivors what so many overseas have given to me in my hour of need.



Financial Analysis and Plan

In the August *Member Update* we called for members who would like a chance at winning a financial analysis and plan, valued at \$1,440 (prepared by the skilled financial planning team at John Cerniauskas Financial Planning Services, Wollongong) to submit their names to go in a draw. This prize was generously donated by John Cerniauskas for our raffle and the original winner when the raffle was drawn in May, Sister Majella McFadden, had no immediate need for the prize and in turn donated it back to the Network so that it could go to a member able to make good use of it. At the AGM, member Helen Tracy was declared the lucky winner. Helen is thrilled with her win which she reports is very timely, and we again thank John and Sister Majella for their generosity in making this prize available.

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.

Polio end-game

The World Health Organization announced in May that there were only 537 cases of polio worldwide in 2001, down 82% from 2000. The number of countries reporting polio had halved from 20 to 10. Polio was endemic in over 125 countries in 1988 when the campaign against polio began. A fascinating website www.endofpolio.org is packed with information on the challenges and strategies of the campaign. A few of the titbits that caught my eye were that there are 20 million people alive today who are disabled by polio, that the total cost of the eradication campaign through to 2005 will be less than 3 billion US (the amount Americans spend on coffee every two months) and that since 1999 nearly 2 billion doses of vaccine have been produced annually. A batch of vaccine takes 12-18 months to make. If it is to retain its potency, it needs to be kept cold, a problem in hot war-torn areas often lacking electricity. Until the mid 90s health workers had difficulty determining whether a vaccine was still potent. Then the invention of a vial monitor (specially treated circles on vaccine vials that turn dark as the temperature rises) eliminated the uncertainty resulting from power failures, hot days etc. Vaccine wastage was reduced by around 25%. On the website a *photograph from Sierra Leone's first national polio immunization campaign in 1999 shows five men wearing 'Kick Polio out of Africa' T-shirts over military fatigues. Unexceptional unless you know who they are leaders of the country's five main warring factions. They were together for the first time.*

One of the problems not mentioned on the website is that the statistics WHO quotes *are often unreliable and sometimes wildly wrong* according to an article by Sanjay Kumar in *New Scientist* (19/11/01). *'National level immunization figures are a myth' says virologist T. Jacob John, advisor to the Indian state of Kerala. He said 'year after year', India reported vaccinating hundreds of thousands more children against polio than the number of doses the country purchased.* Often health workers have been threatened by punishment if they do not meet targets. WHO is revising its estimates after looking more critically at the data countries submit (e.g. 106% of children in a country could not have received their first dose of a vaccine in one year) and comparing data with findings from independent surveys.

Thief pursued by woman on electric scooter

Yorkshire scooter user 50 year old Christine Reilly who has asthma and emphysema had just collected her pension from the local post office when her handbag was snatched. Christine told reporter Paul Stokes that *she just saw red when he grabbed the bag and ran off. I couldn't believe his cheek.* She set off at full throttle, caught up with him and demanded the bag back. The thief handed it back after removing Christine's purse. Christine caught up with the thief again after five minutes and grabbed his jacket hurting her finger. She had to abandon the chase and seek medical treatment. However the thief's conscience was *pricked by her courage.* He sent back the purse and gave himself up to the police. He was jailed for nine months. *I was determined he wasn't going to get away with it,* said Christine.

Last European ever to contract polio?

In November 2001 WHO declared polio to have been eradicated in Europe, after the continent achieved the goal of three years without an indigenous case of the disease. Polio did enter Bulgaria and Georgia from India during this period but the virus was quickly eliminated. Europe is the third region of the world to be certified polio-free; the Americas were in 1994 and the western Pacific in 2000. The last European case was two-year-old Melik Minas who lived in south-east Turkey. He was never vaccinated and contracted polio in 1998 (Guardian 27/6/02).

Book about the puzzles and paradoxes of polio

In June, Dr Richard Bruno's book, *The Polio Paradox: Uncovering the hidden history of polio to understand and treat 'post-polio syndrome' and chronic fatigue* was published. It is full of fascinating little-known details about the history of polio, much useful information about relieving post-polio symptoms and hunches e.g. as to how polio and chronic fatigue syndrome may be related and why polio survivors seem less likely to be diagnosed with Alzheimer's disease. The many paradoxes or seeming contradictions of the polio experience are highlighted through the book e.g. *The extreme exercises and therapies that helped polio survivors to appear 'normal' set the stage for PPS and are the opposite of what you need to do to manage PPS today. In the 1980s, doctors were ignoring and rejecting the same polio survivors whose plight had riveted the attention of the world's medical community and spurred it to action just thirty years before.* Bruno says that to take the leap of faith to cope with PPS you should read the words **POLIO SURVIVOR** again and again taking in the breadth and depth of their meaning. *If you can remember all you have survived and appreciate how you have thrived **in spite** of polio, there can be no question that you have the ability to make the physical and emotional changes necessary to survive and thrive with PPS.* The book is available from Amazon.com for \$US18.17 plus handling.

Polio survivors' falls

Falls have been shown to be more frequent among polio survivors than their able-bodied counterparts. Silver and Aiello recently reported that 64% of survivors they researched had fallen within the last year and that 61% of their falls required medical attention while 35% caused fractures. Age was not related to likelihood of falling but a tendency to trip was (published in the *Archives of Physical Medicine and Rehabilitation*, 2002). An Australian study of risk of falls among polio survivors by Lord, Allen, Williams and Gandevia appeared in the same journal this year. They found that survivors who fall more frequently have weaker lower limbs and greater postural sway. The latter was measured while subjects stood on a foam rubber surface. The authors concluded that *the association between muscle weakness and falls is mediated to a large extent by decreased stability.* And as any survivor with a history of falls knows once you start to fall you usually lack the muscle power to do anything to halt your fall.

Aussie polio survivor created modern swimsuit for women

Swimming champion Annette Kellerman was born in Sydney in 1888. After childhood polio left her with leg weakness she was encouraged to swim and by the age of 10 she was winning competitions. When she was 14 the family moved to London where her father determined to make money from her skills. He announced that Annette would swim 26 miles along the Thames, an unheard of feat at that time. Annette succeeded, wearing a man's tight-fitting, shoulder to hips, one piece swimsuit that left legs, arms and neck bare. At that time women swam in dress and pantaloons combinations. Annette performed as *The Diving Venus* in vaudeville shows at the London Hippodrome wearing her costume. However when she wore it in Boston in 1907 the police were called and Annette was

charged with indecency. Following her court appearance Annette sewed sleeves, stockings and a neckpiece to her costume. By 1910 Kellerman's original costume, plus legs to the knees, had become accepted swimwear for women. She starred in a 1914 Hollywood film *Neptune's Daughter* in which her skinny-dipping scenes caused further scandal. A film about Annette's life, *Million Dollar Mermaid*, starring Esther Williams was released in 1952.

Ed. An Australian documentary about Annette Kellerman's life has recently been made, with the Network lending an old calliper to give authenticity to the production. The film's Director has just advised me that the film is premiering at the Sydney Film Festival in June 2003, and will go to air on SBS TV sometime soon after that. Keep an eye out for it in your TV guides.

Polio survivors bring lawsuit against theatre

Margo Gathright-Dietrich and Bonnie Bonham, wheelchair users due to PPS, have filed a federal lawsuit against a theatre in Atlanta claiming that it violates the Americans with Disabilities Act. According to the Atlanta Journal (25/7/02) the lawsuit claims that the theatre: *segregates disabled patrons into inferior seating locations — either at the far back or extreme sides — and frequently charges the highest ticket prices for these locations; provides a 'handicap corral' at the farthest possible distance from the stage that accommodates fewer than nine wheelchairs; provides people with disabilities poor access to concessions, restrooms and other amenities; requires some disabled patrons to come to the theatre ticket office and pay for their tickets in cash, while allowing non-disabled people to charge their tickets over the telephone; and provides some wheelchair accessible seating in aisles that are sloped, making it dangerous and uncomfortable for these patrons.* Bonnie says she was reduced to tears after an irate usher scolded her because she objected to not being able to sit next to her husband at a show.

Siblings of polio survivors

A Norwegian study titled *Education, occupations, and perception of health among previous polio patients compared to their siblings* was published in the *European Journal of Neurology* (May 2002). The researchers, Farbu and Gilhus, found that the educational levels of the 168 survivors and their 239 siblings did not differ but survivors experienced reduced professional options. Survivors were less likely to be in full time employment at the age of 40 than were their siblings. Compared to siblings, more survivors lived on their own. Survivors rated their total life situations and general health as poorer and reported more frequent pain and tiredness than did their siblings.

'Polio Man', silent polio carrier

BBC News (22/7/02) reported the case of a European man in his late 20s, referred to as 'Polio Man', who is carrying the polio virus but has not developed the disease even though he is immunodeficient. It is thought that Polio Man originally received the weakened form of the virus in the Sabin vaccine and somehow this mutated in his body into the full-strength natural virus. *Doctors were alerted to his case in 1995 when conducting a study into gastric problems associated with immunodeficiency. One test during the study involved analysis of the man's faeces and this revealed the presence of polio. It appears he may have been excreting the live virus for over 20 years.* The head of Virology at the UK National Institute for Biological Standards and Control said: *Although there is no official record that anyone has caught polio from him, it is a possibility. Unvaccinated children could be at risk of contracting polio if their mothers have not passed on antibodies. The man is not likely to be in contact with small children.* The case is very relevant to the ongoing debate about how necessary vaccination programs will be after the 'elimination' of polio. I liked a comment by virologist Professor John Oxford, *No vaccine is safe but it's a damn sight better than the real disease.*

How Will They Know?

Merle Thompson, the Network's Vice-President, and Peter Preneas, our Website Liaison Officer, are joining forces to get an ambitious project off the ground. They want to learn about YOUR unique polio story. As time marches on, we must get our stories recorded before history overtakes us. We each have something to tell, no matter how unimportant you might think it is – so please make the effort today to tell your story for those who follow.

A polio-free world is being envisaged. Already Europe is to be declared polio-free and Australia should follow in the near future.

How many times have people asked you about your polio-derived difficulties with no understanding of what polio is and what it can do to you?

Do your children and grandchildren understand what it was like when you had the initial illness? The isolation and separation; the cruel (by modern standards) hospital regimes and visiting practices; the pain; the effort to walk; the ongoing battle for mobility and independence.

How can you explain the changes which have taken place as you face the problems of the late effects of polio?

It is important that your story be recorded so that:

- you can share experiences with other polio survivors
- your family and friends can fully understand your experiences
- the world can know about this disease which had so much impact on individuals, their families and their communities.

YOUR STORIES MUST BE TOLD ...

To publish a book as the New Zealanders did in *Mind over Muscle* would mean a lot of editing and the cost, effort and stress of publishing would probably put such a project out of our reach. Realistically, sales would be limited which would also make publishing not cost-effective. But there are other ways for our stories to be heard.

Tony and Peter would love to place them on the Network web site so others can learn from them, and Merle would like to prepare a collection for public records. Your stories are part of Australia's history and they deserve to be in permanent records such as the Mitchell and National Libraries, and University medical school libraries.

... SO PLEASE SEND US YOUR STORIES TODAY

If writing or typing is difficult and you have an audio cassette tape recorder just speak to it and record your story for us to transcribe. Please send all contributions, whether by mail, email or audio tape, to Peter and Merle at the Network. And please don't leave it too long before we hear from you!



A Cheeky Possum Competes in Melbourne

Christine Williams

Our hard-working Webmaster, Tony Marturano, is well known to regular readers for the other passion in his life: archery. Tony travelled to Melbourne in October to compete in the World Masters Games. He reports that the opposition was tough but he had a good week of competition and was content with his performance. Through the fellowship of polio survivors around Australia, Tony was put in touch with Christine Williams, who later recounted some of his exploits in the newsletter of Victoria's Western Region Polio Support Group. Christine's article and photo are reproduced here with her and Tony's kind permission.

During the recent World Masters Games, it was my privilege to meet two delightful fellow polios - Andre from Perth (a gentle soul who stayed at my home), and Tony from Sydney (a cheeky possum who was a daily visitor). Needless to say, most of my friends have given me heaps for keeping company with not one, but two bachelors!

For me, highlights of Andre and Tony's visit included attending the Games Opening Ceremony (unfortunately, the acoustics were atrocious); dining alfresco in St Kilda's red-light district (Andre's suggestion, not mine!); watching the guys and our Wayne competing in indoors archery; and having afternoon tea with Wyndham's Deputy Mayor.

A special treat was sharing a delicious Burmese meal (lovingly prepared and provided by Andre) with the guys and some of my single friends. Somehow, Tony even persuaded fellow archer Paul, who is a professional guitarist and singer, to call by after dinner to entertain us. It certainly was a memorable night.

I wasn't surprised to discover that Andre and Tony are typical of so many polio survivors - high achievers, and multi-talented. Towards the end of their stay I no longer had the stamina to keep up, so took a raincheck on accompanying them to Crown Casino. Tony seemed especially pleased that they had brought chaos into my orderly life for a week!

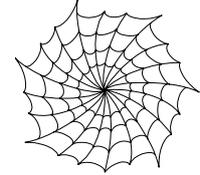
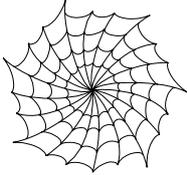


To conserve his energy at archery events, Tony uses a scooter to get around. He says "I have my scooter now nothing can stop me".

Tony's recent results at the NSW State Championships are proof of this. Over the weekend of 23 and 24 November, Tony won the Veterans 50-59 Recurve Division for the second year in a row - and he did it with an equal National Tournament Record. Tony also won the disAbled Event and placed 5th in the Open Event.

Well done!

Christine hitching a ride with Tony at the World Masters Games Opening Ceremony



Cobwebs is a new feature in Network News which will be brought to you by Peter Preneas. Cobwebs will bring you up-to-date information on our web site, tell you what you can find on the site, and show you how to get the most out of your visit to its pages.

Our web site is growing and there should be something of interest to suit just about everyone. We are particularly proud of the fact that we now offer one of the most credible sources for information about polio and its late effects, and the way Tony has structured the web site enables it to benefit anyone needing hard and fast information.

The Network's web site was always going to be successful, especially housing all of Gillian's Newsletters dating back to November 1995 (so far). Include the Post-Polio Networks accumulated knowledge, then stir in some of Tony Marturano's computer talents, and the result is www.post-polionetwork.org.au.

At the moment we receive over 150 visitors a day, this is usually made up of polio survivors, doctors, physiotherapists or just students who may have an assignment. The web site certainly provides a very important link from the past to the present for anyone trying to understand polio and its after effects.

I'd like to take another opportunity to appeal to any of our readers who may have a polio story or possibly some photos. We would love to hear from you. As an Australian web site we would like to share with the world the Australian Polio Story. All photos posted will be returned. Your stories can be emailed or posted to me at the above addresses.



Reunion of Polio Patients and Staff - 25 October 2002

An assembly of about 85 people gathered at Burwood RSL for a second reunion of polio survivors and nurses who cared for them. The first reunion in June 2000 was initially planned for Prince Henry Hospital Polio patients from 1950 and other years but others also participated and this was again the case this year. Guests came from afar, the furthest being Des Kerrigan (PHH 1950) and his wife Jacquie from Adelaide. This reunion was held in response to promptings from those who had attended the first and, judging by its success, it will be repeated.

A most outstanding feature of the recent gathering was the attendance of more than a dozen nurses who had trained at Prince Henry during the "Polio Years". This hospital, once called The Coast Hospital, was the main centre in NSW for treatment of patients with infectious diseases.

The guest of honour and keynote speaker was Professor Richard Jones who was medically involved with the Hospital for almost four decades. All those attending, judging by the numerous questions asked, were enthralled by what he had to say. Many who had been in Prince Henry joined in with their reminiscences and shared with us their recollections of other patients. Gabby Hannemann who is one of the younger members of the Network but one of the "longest residents" of Prince Henry assisted Professor Jones to recall some of their mutual acquaintances. Lynne Ellis recounted her meeting with Sister Kenny, and had the photos to prove it!

Professor Jones was accompanied by his wife, Mikki. Following his talk, he presented the Network with a tie and a mug featuring Prince Henry insignias, together with a generous donation.

Despite the cheerful, friendly occasion there was, to a certain extent, a memorial atmosphere even one of mourning on the part of former Prince Henry patients as Professor Jones and others reflected on the imminent closure of the Hospital.

Support Group News

Neil von Schill
Support Group Co-ordinator

Phone: (02) 6025 6169
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Many thanks to **Bernie O'Grady**, Convenor for Blacktown and the Lower Blue Mountains, and his team for representing the Network at a Disability Expo held at Penrith Panthers Pavilion on 12 and 13 July. It is very important that we take opportunities such as this to make the activities of the Network visible to the public. The time and effort devoted by Bernie and his members in manning a site at the Expo is very much appreciated.

The Blacktown-Blue Mountains Support Group continues to grow in strength and has now reached 12 members. They meet on the 3rd Monday of each month from 11:00 am to 1:00 pm at Kingswood Community Centre, corner Bringelly Rd and Baden Powell Avenue, Kingswood.

Convenor, **Bernie O'Grady**, would like to pass on these comments and very useful advice. *"During a rare period of quietness at our March meeting a comment was made by one of our members, Helen. She queried whether anybody had observed the vast difference in age of the group. Our youngest member Les is aged 41 while our most senior citizen, Alec, is 84. Les said that when he enquired about joining the group he really believed and expected to meet people at his first meeting much older than himself. Alec, who contracted polio at age 37, was married and had teenage children, expected to meet people a lot younger than himself."*

"There are a lot of people", comments Bernie, "who would like to join a Support Group, but think they are either too old or too young, but as you can see from our group, age is no barrier. In fact, it is very interesting to listen to each member who contracted polio at different ages to be able to share their story and how each person can relate to the other in the memories that they have of the acute stage and recovery."

At its May meeting the Management Committee agreed to add another classification to our support network, that of Regional Representative, to broaden and strengthen our presence in the community. At present we have Support Group Convenors in both city and country areas and one of their duties is to facilitate contact between members in their locality through organising meetings or by providing telephone support.

The role of a Regional Representative would be to act a reference person in their local community for the Post-Polio Network (NSW) Inc. Their responsibilities could include promoting the benefits of being a member of the Network, advising people how to join the Network, referring potential members to other personnel (eg President, Support Group Co-ordinator), helping promote Post-Polio Awareness Week, advising the Support Group Co-ordinator of whether there is a need to establish a Support Group in their area.

The position would not be an onerous one nor a time consuming one. It IS NOT the Regional Representative's task to establish Support Groups nor convene and chair meetings. A person accepting the position, however, would have to consent to having their contact details (name and phone number) published in *Network News* and on the Network's website.

If you are interested in offering your services to be a Regional Representative in your local area or you would like more information, or you would like to discuss the position, please contact me on (02) 6025 6169. A short set of guidelines has been prepared. I will provide every assistance to any member who is interested in becoming a Regional Representative.

Over the past two years, to help me with travel in carrying out my role as Support Group Co-ordinator, I have been funded by the Rotary Club of Albury North. The Network has received almost \$2,400 in donations from the Rotary Club for which we are extremely grateful. As a result of my involvement with this local Rotary Club I was nominated for an award which is presented to people with disabilities who are making an outstanding contribution to their community, and who, by their actions, serve as *Shining Examples* to the community. Rotary Clubs throughout Victoria and southern NSW participate in the award scheme and at a Rotary Changeover Dinner at the end of June, I was very honoured to be presented with a *Shine On Award* for my endeavours both with the Network and other community organisations.



In early September I undertook another trip with the prime objective being to share in the 10th Anniversary celebrations of the **Hunter Area Support Group**. Along the way I was able to meet with **Orange** Convenor, **Susie Simmons**, along with members **Max and Leonie Barrett**. We enjoyed lunch together and discussed arrangements for an inaugural face-to-face meeting for members in the Orange area. A report on this meeting will appear in the next newsletter. In **Dubbo** I caught up with local Convenor, **Gregg Kirkwood**, as we made preliminary arrangements for a **Country Conference** to be held in Dubbo next September. Further details of this event will appear in 2003.

Whilst in Dubbo I also took the opportunity of meeting **Elizabeth Woods** who has undertaken the responsibility of convening a group for members in Sydney's **Northern Beaches** area. Elizabeth and her husband Frank were enjoying a short holiday in Dubbo and I was very pleased to make their acquaintance. Elizabeth worked very hard to help us organise a most successful inaugural meeting of members living in the Northern Beaches region which was held at Dee Why RSL Club on Sunday 29 September. It's great to see another metropolitan Support Group up and running.

On reaching Newcastle I was delighted to be able to share in the 10th Birthday Celebrations of the **Hunter Area Support Group** which was our first Support Group formed and is currently our largest group. Toronto Workers Club is an excellent venue and they provided a wonderful lunch. Chairperson **Barbara McCormack** and Convenor **Wendy Chaff** organised an entertaining program and a memorable day was enjoyed by all in attendance. We were joined by President **Gillian** and Treasurer **Bob Tonazzi** who travelled up from Sydney for the day. Congratulations to the Hunter Group for having achieved this notable milestone.

While staying at Muswellbrook I took the opportunity of visiting **Bruce Buls** who is Convenor of the **Upper Hunter Support Group**. Bruce was looking forward to attending the Second Reunion of Polio Patients and Nurses and taking along some memorabilia.

In closing I take this opportunity to wish everyone a restful Christmas and a peaceful New Year. A complete list of Network Support Group contact details, meeting dates and venues for 2003, together with contact details for Regional Representatives, will appear in the next issue of *Network News*, due out in February.

Mountains to Magnets

Jean Underwood

Magnets have also been in the media a lot lately although to date there is little scientific research into their efficacy or otherwise. Member Jean Underwood has found them to be beneficial and has recounted her experience for the benefit of other members. Jean is happy to talk to any members wishing more information – you can contact her on (02) 6253 9199.

As with any treatment, therapy or device that we report on in Network News, what may help one member will not necessarily suit another, so we urge you to do your own research and make your own decision about whether a particular treatment, therapy or device is right for you.

Over the years I have read about the personal battles of many other polio survivors. I'd never thought of telling mine because compared with others it was not at all remarkable. Now I feel I do have something to tell that may be of interest to fellow Network members.

In 1938, my family interrupted their Sydney holiday because of the polio outbreak to return to what they believed to be the safety of Tasmania's West Coast. My two cousins and I were 'quarantined' but it didn't protect us and the three of us ended up in the Queenstown Hospital. Memories of what I experienced there surfaced later in adult life. However, I didn't suffer the kind of psychological pain of separation that others have suffered as I was kept at home when my friends were moved to Wingfield in Hobart.

In many ways, I've been one of the lucky ones. I managed reasonably well over the years with teaching, parenting and home duties until the 1970s when the fatigue, pain and the accompanying confusion of post polio led to a major revision of my way of life. Eventually, I was invalidated out of teaching but had the good fortune to enter a new phase of my career in curriculum resource development. I also learned to pace myself and was quite sure that I was in control of the situation.

At the age of 65 years I gained a permanent, full-time position as an instructional designer on distance education materials. But I hadn't factored in work injuries like the loop of telephone cord that wrapped itself around my right (polio affected) ankle. I sustained a nasty traction sprain that introduced a whole new set of symptoms. I limped badly, required lengthy rest periods, swigged anti-inflammatory concoctions and ... generally struggled. Needless to say, I was not amused that my plans for a happy, unfettered retirement were now threatened by a permanent injury. For over three years, I tried to resolve both the physical and legal/insurance issues but by August last year I was still in pain, out of alignment and out of balance. I planned a retirement date, but attitudinally I was disappointed and not at all optimistic. My retirement, I thought, would now be governed by physical constraints – I'd looked forward to actively enjoying my grandchildren, my gardening and my 12-acre property.

But we should never despair – each time I've thought I'd reached the end of the road with nowhere else to go something has happened to open up a new future with lots of opportunities - and this was about to happen again. And it happened with a bracelet which was an early birthday present from my son and family. They'd already experienced the benefits of a magnetic sleep system and were keen to ease my pain and improve my mobility. At this stage, I did not understand what they were offering – and this is important because afterwards people would say, "It's probably all in your mind". There was nothing in my mind then – I was grateful for the gift and wore it around my ankle – I'd no idea what they hoped it would do for me.

What it did two to three days later was to improve my energy level and freedom of movement. After the bracelet, came another gift in the form of the magnetic soles which I've worn in my shoes ever since. The insoles combine magnetic and infrared technology and traditional acupuncture; now there was a very definite difference – not only in my energy levels but my sense of balance. I can't remember experiencing such balance as this for years. Convinced now about what magnets could do for me, I graduated to the "sleep system" which consists

of the magnetic pad on top of my mattress, a cosy comforter composed of ceramic fibres that maximises the warmth of the body, and a magnet pillow. As well as a general sense of well-being, the significant change was that I no longer had muscle spasms. They return though if I'm away from my bed for a time. At this point I must introduce my "lifesaver" (known as a Magboy) because it really is a case of: "I wouldn't have believed it if I hadn't seen it for myself". While visiting my son I experienced a particularly fierce spasm that twisted my foot at right angles to my body. He and his wife each grabbed a Magboy (theirs and mine) and began "spinning" the magnets, away from my foot, to create a magnetic field. As I didn't know that that's how you use them I became more and more alarmed that they weren't massaging me to give some relief. I was therefore amazed when my foot moved back into position of its own accord, my toes wriggled and the spasm was gone. There were none of the usual painful after effects and I had a restful night's sleep. Now I always carry the Magboys with me as an emergency kit especially when I'm travelling and away from my own bed.

As I'd been helped by the magnets, I wanted to let others know about them too. It's knowing that I've ready access to a source of relief that has made the difference to me. I've now exchanged my education career for the opportunity in health and wellness and sharing my days with people rather than computers. My plan is to meet with as many Post polio Support Groups as possible to show them the magnetic products and talk about what I know about magnet therapy within the context of a whole range of therapies that help me – I value my doctor, my physiotherapist, my Alexander teacher and my acupuncturist and now I value my magnets!



Vale – Hugo Orro (12-11-32 – 15-10-02)

Brian Toby

We were saddened recently to hear that Hugo Orro had passed away. Hugo had been a Network member for many years, and was a valued Network Support Group Convenor. His good friend and fellow member Brian Toby sent in this eulogy celebrating Hugo's life.

Hugo was a refugee from war-torn Estonia and arrived on Australian shores aged 16 in 1949. His mother and brother were in Victoria and Hugo in NSW where he contracted polio in 1950/51. With no family near and as yet few friends one can imagine how grim all this was. (I've heard stories about the boy in the isolation room from others since, but he never referred to this time at Prince Henry Hospital.) I first met Hugo in July 1952 at Jervis Bay Rehabilitation Centre where he was making his way as well as possible. He walked with crutches and long calipers. I remember well the bachelor's room he had in the Estonian colony in Cabramatta on his arrival back to Sydney with no work and little prospect. Though I was working I shared many a "glass of cider" back in those first years.

Then his life took a twist (thank God for life's twists) and he was converted to the Church of Jesus Christ of Latter-Day Saints (Mormons) and about that time he landed a position in a near-by library as a book binder. He applied himself to study (his hand was weak for writing) and in no time became a librarian at Springwood. During all this he had met and married his wife, Anne, who was the organist in his Church. From there on it was all "up" for some years. He and Anne had eight little Australians and three different homes. But his disabilities started to wear. He had always had a habit of "dozing off" into deep sleep. When this happened at Council meetings some were not impressed! He had a massive heart bypass operation and his eyesight grew weak. He was forced to accept early retirement and bought himself a retirement home on a mixed farm outside Wellington. Ever a man to do things "his way"! He also became a Support Group Convenor for the Post-Polio Network in that area.

The last time we met he said he doubted he'd make the big "70" and sure enough he just missed out on reaching 70 years of age. Despite his feeble health and earlier setbacks he had an indomitable spirit and determination. His life was long, strange, and well, kind of inspiring!



We recently wrote to Her Excellency Professor Marie Bashir AC, Governor of NSW, to introduce the Network and its membership to her. Our letter and the Governor's prompt response are given below.

Our letter ...

Members of our Network were very pleased to hear your address at the Prince Henry Hospital 121st anniversary function in September. It was particularly pleasing to hear of your awareness of polio as a major cause of admission to the hospital and of the hospital's role in the treatment of those who contracted this disease.

The Network's membership was well represented at the Hospital's celebrations and our stall also attracted a lot of interest from ex patients and staff. Unfortunately, we did not have the opportunity to meet you personally and so were unable to let you know about the role of the Network in supporting polio survivors, many of whom are now experiencing the late effects of the disease. To the general community, and even among some in the medical fraternity, polio is not understood or is regarded as a thing of the past. It does, however, still have major implications for the many tens of thousands who survived the initial illness, have led fulfilling lives and are now experiencing polio's debilitating late effects. I have enclosed for your interest a copy of our information booklet *Helping Polio Survivors Live Successfully with the Late Effects of Polio* which further describes the important work of the Network.

In your address you mentioned that there were members of your own family who contracted polio. We would be very pleased to offer them information if they would be interested.

The Governor's reply ...

Thank you for your gracious letter informing me of the work of the Post-Polio Network (NSW) Inc, and the important role which members play. Fortunately my two cousins, who contracted the disorder during their childhood in the 1930's, are keeping well. With best wishes in all your efforts.

Member Mary Le Clair recently sent this "note of caution" about what is likely to be a very important purchase for many of us as we rely more on wheels than legs.

I have used electric scooters for some 6 or so years and have had an experience with a dealer that was very unsatisfactory, in fact I would say distressing. Consequently I forward for your consideration the following thoughts. It is really important to:

- Only use people highly recommended by someone who has used scooters for a period of time.
- Make sure repairs and service are done on the premises.
- Get in writing their policy re a trial period. Then
- DO NOT believe the sales person's description of "what it can do". Trust your own judgement after a trial period of at least 24 hours.
- Do not trial it with the sales person present.
- Make sure you do not buy without someone with you. Sometimes a family member is not the ideal help, being too close. I have been known to call a Rotary friend when I have needed advice or moral support.

Should anyone care to talk to me about scooters please feel free to call me on (02) 9953 5415 or email me on mleclair@localnet.com.au.

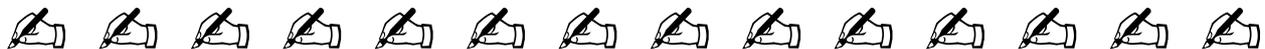
We send our Newsletter to many post-polio support groups around Australia and overseas. In a recent letter from the Sunshine Coast Post Polio Support Group, the Convenor invited any Network members travelling to or through their area to drop by. You can contact the Group at PO Box 127, Cottontree Qld 4558.

Dear Friend

Excuse me for taking the liberty of calling you friend, however as we receive the newsletters from various groups they are eagerly handed around amongst our group and its great to read about our friends in other states and how they are coping and getting on with their lives.

Our group has been functioning on the beautiful Sunshine Coast of Queensland for over eleven years now. For those who are not familiar with the area, it stretches from Caloundra in the south to Noosa in the north with Mooloolaba, Alexandra Headlands and Maroochydore in the middle. We also have a large hinterland area including the picturesque Blackall Range towns of Montville and Mapleton.

We have a happy and lively group and would love to meet any NSW members who are on holidays in our area or if heading north for the winter. Of course if you were moving north permanently we would encourage you to make contact as we welcome new members with open arms.



Seminar Program 2003 – Dates To Remember

Saturday 1 March	Northcott Society <i>North Parramatta</i>	A panel of orthotists will discuss their particular areas of expertise with regard to the prescribing and fabrication of orthoses, and the different materials available <i>Further details will be given in the next issue of Network News</i>
Saturday 21 June	Maroubra Seals Sports Club <i>Maroubra Beach</i>	Special General Meeting to consider Constitution Following lunch (to be provided) there will be an Open Forum for members to discuss and debate future directions <i>Further details will appear in upcoming issues of Network News</i>
Weekend 6 and 7 September	Showground Expo Centre <i>Dubbo</i>	Planning has commenced for this exciting weekend which will include a full-day Mini-Conference and Support Group Convenors Workshop <i>Further details will appear in upcoming issues of Network News</i>
AGM and Seminar	The date, venue and topic for our 2003 AGM and Seminar will be advised	



The Management Committee wishes
every member a
Happy and Holy Christmas
and a
Healthy and Peaceful New Year