POST - POLIO NETWORK (NSW) INC.

NEWSLETTER

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President's Corner

Gillian Thomas

Welcome to regular readers and new members alike. Publicity for the Network and the late effects of polio got off to a flying start early in January when I was interviewed on ABC radio (in both Sydney and Canberra) and on 2CBA FM in Sydney. As a result of these interviews my phone rang hot and I sent out almost 60 information kits, with more than a dozen people already becoming members.

On 23 December 1999, Paraquad Victoria cancelled the *Polio 2000 Conference* less than a month before it was due to commence. I am very happy to report that following very fast, serious and effective networking between the Australian and New Zealand Polio Networks, the Conference did in fact go ahead on 19-21 January, under the auspices of *Polio Australasia* (the collective Australasian Networks). I spent the Christmas / New Year period contacting PPN registrants and representatives from the other Networks and requesting that they hold off cancelling their travel plans until we could see if the Conference could be salvaged. I am indebted to the other Networks who added their voices of protest to ours to insist that the Conference go ahead. To my delight, the following PPN members were still able to attend and I thank them sincerely for their patience and understanding as Conference planning was reactivated: Roma Gater, Norma and Len Hinde, George Laszuk, Neil von Schill, Joan Thomson and Amy Zelmer. It was good to be able to spend time with them. I also must thank Jeanette Marshall of Polio Network Victoria for her magnificent effort in getting the Conference back on track once *Polio Australasia* took it over. Despite losing the international speakers, the local speakers rallied around and presented an interesting and varied program. To give you a taste of the quality of the presentations, I have included on pages 3 to 5 the paper by Dr Keith Hill entitled *Risk of Falls and Injuries in the Older Person with Polio*. The Conference sessions were recorded and tapes will be available through the Network. An Order Form will be included with the next *Newsletter*.

One positive outcome of these events was that the representatives of the various Networks in Australia and New Zealand agreed at the meeting of *Polio Australasia* after the Conference to work together more closely in the future. Our first co-operative effort is likely to be arranging a visit to this part of the world in June 2001 by American polio survivor and researcher Dr Lauro Halstead. More on that in the next *Newsletter*.

Thanks to the generous donation of time and talent by member Lynne Ellis, our *Newsletter* is now available on audio tape for members who are unable to read it. To date, two members are benefiting from this service, but there are undoubtedly others who would also appreciate receiving the *Newsletter* on tape. Our Membership Liaison Officer, Janet Malone, will shortly be ringing around our older members to see if this alternative format would help them. Please let Janet know on (02) 9787 1042 if you, or any member you know, would like the *Newsletter* on tape.

At the Committee's meeting in January we talked about our goals for the upcoming year. Thank you to those members who took the trouble to contact me with ideas. The Committee has decided that the following will be given priority over the next 12 months: submitting an *Expression of Interest* application to the NSW Department of Health seeking funding, producing a Medical Alert Card and a Hospital Admission Fact Sheet for issue to all members, developing a database of doctors knowledgeable about the late effects of polio, and implementing a publicity strategy to raise the Network's profile whenever and wherever possible.

On a personal note, I was very pleased to be advised just prior to Christmas that I have been selected to be a Community Torchbearer for the *Sydney 2000 Olympic Torch Relay*. My trusty scooter and I will be carrying the torch on 14 September in the Randwick area, but the exact route won't be advised until the end of July. I would be grateful for your support by the side of the road on the day, and hope that you will wear your Post-Polio T-shirts and badges to hopefully gain some much-needed publicity for the Network. If any other member is carrying the Torch, please drop me a line so we can publicise the details in the *Newsletter*.

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Post-Polio Network Seminar

Date: Saturday, 4 March 2000

Time: 11:00 am - 4:00 pm

Bring a packed lunch to eat from 11:00 am
As usual, fruit juice, tea and coffee will be provided

Venue: The Northcott Society
2 Grose Street, Parramatta

Ample parking is available in a car park at the end of the street (the venue is then a 100 metre walk away).
Limited parking is available on the premises. It would be appreciated if those who are more mobile would leave this closer parking for members who are only able to walk or wheel short distances.

Our first Seminar this year focuses on historical views of polio. Starting at **11:00 am sharp** Mary Westbrook will give a brief introduction to the film **A Paralysing Fear**, including how it came to be made, prior to its screening.

What you will see is the full (90 minute) version which contains additional material to the program shown on ABC TV last October - it includes many more details of people's personal experiences with polio. The following description of the film tells of the fear of polio in America: "It was not long ago that our nation was held hostage to terror, not from war or nuclear attack but from a frightening disease that seemed to come out of nowhere. *A Paralysing Fear* is the story of the terror told through the mesmerizing recollections of polio victims, their families, doctors, nurses, scientists, researchers, and fundraisers as they fought this deadly virus". Immediately following the documentary, a half-hour program about the late effects of polio, featuring Dr Lauro Halstead and Hugh Gallagher (both polio survivors), and polio in the world today (discussing immunisation issues) will be shown. Please bring your lunch and eat it while watching the films (but no rolling Jaffas down the aisles please!)

At the conclusion of the screening there will be a break for approximately half-an-hour to give you a chance to have a cuppa and stretch your legs.

At **1:30 pm**, **Carol Mara** will give us an insight into her motivation in writing ***Iron Cradles***, and the research required to make it such a powerfully evocative account of polio in the 1950s. To quote from the notes on the back cover of the book: *Iron Cradles tells the story of one country family whose baby daughter, diagnosed with polio, is banished to a Sydney hospital and into isolation. With depth of characterisation and a wonderful talent for storytelling, Carol Mara shows us a small town's attitude to the contagious disease and to the family who are now considered by many to be tainted. ... Iron Cradles is a thought provoking and very moving exploration of a family in crisis, of powerlessness in the face of authority and ignorance, and of finding resolution.*

Carol will have copies of her book for sale, and if you have already purchased a copy, bring it along and have it autographed.

If this is the first Seminar you have attended, please introduce yourself to a Committee member. We look forward to seeing everyone there.

Risk of Falls and Injuries in the Older Person with Polio

Dr Keith Hill

Physiotherapist Dr Hill is Co-director of the Falls and Balance Clinic, National Ageing Research Institute, P0 Box 31, Parkville, Victoria 3052. He presented this very interesting paper on 19 January at the Polio 2000 *Conference in Melbourne, and it is reproduced here with permission of the Conference organisers.* ***An audio tape recording, which complements this paper, is available from the Network for $16, including postage.***

Balance problems and falls among older people

Falls are common among older Australians, with approximately one third of all people aged over 65 years living in the community experiencing one or more falls in a 12 month period. A relatively small proportion of falls cause serious injuries requiring hospitalisations, but many falls, even those which do not cause any obvious injury, can cause a marked loss of confidence or fear of falling. Loss of confidence in mobility can cause an older person to curtail various forms of activity and exercise, which over time can result in further weakness and balance problems, and increased risk of further falls.

Falls are commonly described as having an intrinsic or an extrinsic cause. Intrinsic falls causes consist of age related decline in function in each of the components of the balance system, as well as pathology or disease in any of the components of the balance system. Examples include glaucoma (vision), peripheral neuropathy (somatosensory) or stroke (multiple systems). Some medications have also been associated with an increased risk of falling, for example, long acting benzodiazepines. Muscle weakness, as in polio, is also an intrinsic falls risk factor. Extrinsic causes of falls consist of high falls-risk activities (for example, standing on a chair on a table to change a light globe), as well as any environmental factor contributing to the fall. Examples of these include cords on floors, uneven footpaths, wet surfaces, and poor lighting. Many extrinsic falls risk factors are avoidable with care and planning.

It should be noted that in many cases, there is a combination of intrinsic and extrinsic falls risk factors contributing to an individual's risk of falling. A key component of the management of a person who experiences a fall is to identify which intrinsic and extrinsic falls risk factors were in play for an individual's fall, and to work together to develop a management plan to address these. Often, a multidisciplinary assessment and management approach is necessary, including medical, physiotherapy, and occupational therapy input. Other professionals such as podiatrists and clinical psychologists (for management of fear of falling) may also have a role.

Many people consider falls to be an inevitable consequence of growing older. However, this is not the case. It is true that balance abilities, and performance in each of the components of the balance system, are not as good in an older person as in a younger person, but these changes are relatively small relative to the capacity and reserve within the balance system. It is when some form of pathology is superimposed onto the effects of ageing on the balance system that significant falls risk can develop.

Falls risk factors

A number of studies have investigated risk factors for falls. These include.

- history of previous falls
- female gender
- chronic medical conditions such as stroke or Parkinson's Disease
- poor balance and mobility
- reduced activity level

- poor vision (acuity / contrast sensitivity / depth perception)
- multiple medications, and some medication types such as long acting benzodiazepines
- impaired cognition

The risk of falls is greater the more falls risk factors an individual has.

Falls risk and the person with polio

Given that muscle weakness is an important intrinsic risk factor for falls, people with polio will have an increased risk of experiencing falls. However, this issue has received very little research focus. The musculoskeletal problems associated with polio have usually remained stable over many years. Superimposed on the underlying musculoskeletal falls risk factor is the effect of increasing age on each component of the balance system, which although small, does increase falls risk. Falls risk is further compounded by the presence of other intrinsic health problems affecting components of the balance system.

Assessment procedures

Any person who has a fall should inform their general practitioner about the fall, and discuss the circumstances and any problems (including loss of confidence) resulting from the fall. Any new symptoms, even if they do not clearly seem to be related to the fall, should be discussed. An important symptom to discuss is dizziness, as it can cause considerable loss of function, reduced activity, and impaired balance. Changes in pain, and joint range / flexibility, and activity level also should be reviewed.

There are many methods which have been described to evaluate balance performance. The aim of using these measures is to identify if a problem exists, to quantify the magnitude of the problem, and to be able to identify change in performance over time (improvement or deterioration). These measures may also provide some information to the physiotherapist about the type of exercises and activities which may be useful in a treatment program. Examples of some simple clinical measures of balance performance which have been reported, and scores achieved on these tests by healthy older people are described below (references Bernhardt et al, 1998, Hill et al, 1999).

- Functional Reach test — 30 cm
- Step test — 17 steps / 15 seconds
- Timed Up-and-Go test — 9 seconds
- Walking Speed (comfortable) — 79 metres / minute

Balance assessment may also include evaluation of performance under "dual task" conditions, which are more representative of the way in which we have to balance in everyday activities - that is, we don't always have the luxury of devoting all of our attention to balance, as we often do under the artificial test conditions in the doctor's or physiotherapist's assessment office. For example, walking may be assessed while talking, or turning the head side to side (as in crossing a road checking for traffic).

Physical assessment will also involve evaluation of the various components of the balance system, including muscle strength, joint range of movement and muscle length, joint proprioception, coordination, and muscle tone.

Management options

The options available regarding management will be dependent upon the assessment findings.

Commonly, exercise is prescribed as an intervention for reducing falls. This may be in the form of a set of exercises to be performed daily at home, or may be exercises conducted in a group

setting. It seems clear that to be beneficial in reducing falls risk, exercise programs need to incorporate a balance component. Evidence from a randomised controlled trial of women aged 80 years and above has shown a home exercise program to significantly reduce falls rates (Campbell et al, 1997), and similar trends were observed for a group exercise program (Lord et al, 1995).

It is important the exercise type and dosage be selected carefully and monitored closely for the person with polio, as excessive exercise may cause increased pain, and paradoxically, increased weakness. Nonetheless, this type of program can be conducted effectively with older people with polio.

A walking aid can provide increased stability during walking if used effectively. It can also increase the symmetry of walking, which may help to relieve some strain on the lower back and hips over time. As such, walking aids can be used to reduce risk of falls. Changes to a walking aid (starting to use one, or changing from one type to another) should be done in consultation with the doctor and / or physiotherapist. This will ensure that treatable problems increasing the need for the walking aid can be identified and treated, as well as ensuring that the correct walking aid is used, that it is the correct height and that it is used correctly and safely.

Safe footwear is very important in reducing falls risk. Shoes should have a low broad heel, non-slip surface, and provide firm support.

Hydrotherapy

Exercise in water can provide valuable benefits for people with polio at risk of falling. In a pilot study at Grace McKellar Centre, Geelong, a once weekly hydrotherapy program achieved improved overall leg strength, improved balance performance, and reduced falls. Hydrotherapy is a very effective medium for exercise because of the added effects of the warm water, and the use of buoyancy and resistance in the water.

Additional issues to consider

Falls risk can often be reduced following comprehensive review and individualised management. However, in some people, the risk of serious falls remains high. A number of strategies can be used in these situations. For example:

- use of a personal alarm, so that help can be sought quickly if a falls does occur,
- use of hip protector undergarments, which can be worn to reduce the likelihood of hip fracture.

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The Role of Activity

James Agre, MD, PhD

James Agre received his MD from the University of Minnesota in 1976. He completed residency training in Physical Medicine and Rehabilitation in 1979, and received a PhD in Physical Medicine and Rehabilitation in 1985 from the University of Minnesota. He has written many articles on the results of his research on post-polio syndrome (published in the referred literature) and has presented at many conferences. He is a firm believer, both professionally and personally, in regular exercise.

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"To exercise or not to exercise, that is not the question for polio survivors; rather, the questions are these: what amount of exercise is enough? *what amount is too much?"*

There is no easy answer for all polio survivors, but we can make some general observations about inactivity and exercise.

Adverse Effects of Inactivity

Limitation in physical activity results in progressive deterioration of cardiovascular performance and efficiency; metabolic disturbances; difficulty in maintaining normal body weight; disturbed sympathetic nervous system activity; reduction in muscular strength and endurance; and possibly emotional disturbances.

Beneficial Effects of Regular Exercise

In contrast, beneficial *physiologic* adaptations to regular exercise include reduction in heart rate and blood pressure; morphologic changes in skeletal and cardiac muscle resulting in improved physical work capacity and an enhancement of cardiovascular efficiency in delivering oxygen and nutrients to the tissues; increased muscular endurance; increased myocardial vascularity; reduced blood coagulability, reduction in adiposity and increased lean body mass; increased cellular sensitivity to insulin; and favorable changes in blood lipids and cholesterol.

Beneficial psychological changes from regular exercise include reduction in muscular tension; improved sleep; and possible increased motivation for improving other health habits such as changes in diet (reduction in saturated fat consumption. for example) and cessation of cigarette smoking.

Evidence for Beneficial Effects of Exercise in Post-Polio Individuals

Studies have shown strengthening exercise, aerobic conditioning exercise, and ambulatory exercise to be beneficial.

Strengthening Exercise In Feldman and Soskolne's study of six post-polio patients, the subjects performed non-fatiguing exercise three times per week for 24 weeks or longer. Strength either increased or remained the same in all muscles in all subjects except for one muscle in one subject that became weaker. The authors concluded that the strengthening exercise was, in general, very beneficial.

Einarsson and Grimby studied 12 subjects who exercised three times per week for six weeks. The subjects performed intervals of strengthening exercise interspersed with rest breaks. All subjects became significantly stronger in the six-week period.

Fillyaw and colleagues studied 17 subjects who exercised every other day for up to two years. The exercise intervals were interspersed with rest breaks. Over this period of time, all subjects gained significant strength.

At the University of Wisconsin we conducted a 12-week study of muscle-strengthening exercise in seven post polio subjects. Subjects exercised four times per week for 12 weeks at home. Exercise intervals were interspersed with rest breaks. After the 12-week program, the average increase in strength was 36%; also work capacity and endurance increased by 15% or more.

Aerobic and General Conditioning Exercise Four such studies have been performed. Jones and colleagues studied 37 post-polio subjects: 16 volunteered for the exercise program while 21 served as control subjects. The exercise subjects performed stationery bicycle exercise three times per week for 16 weeks. They began with bouts of exercise of 2-5 minutes on the bicycle with 1-minute rest breaks, progressing up to 15-30 minutes of exercise per session. After the program, the exercise subjects were found to have significant improvements in their aerobic power and their capacity to exercise. The control subjects did not change in this same time interval.

Kriz and colleagues performed a similar study in 20 post-polio subjects (with 10 exercise and 10 control subjects); however, the exercise was upper-limb cycle ergometry (rather than lower-limb cycle ergometry). In this study, too, exercise subjects significantly increased their aerobic power and exercise capacity.

Grimby and Einarsson studied 12 post-polio subjects who performed submaximal endurance and strength training twice weekly for six months. Activity was interspersed with rest breaks. Except for one, all subjects were significantly improved from the training program. The exception reported excessive fatigue with the training program. Grimby and Einarsson concluded that combined endurance training and submaximal strengthening exercise can be generally positive in post-polio individuals, but that overtraining can occur.

Prins and colleagues studied 13 post-polio subjects. Nine performed a swimming and aquatic strengthening exercise program and four were controls. Intervals of exercise were interspersed with intervals of rest. The authors reported significant improvements in strength and flexibility in the exercise subjects and no change in the control subjects.

Ambulatory Efficiency Dean and Ross studied 20 post-polio subjects. Thirteen were control subjects and seven performed treadmill walking exercise three times weekly for six weeks. The exercise was low-level, non-fatiguing, and not painful. After the six-week program, the exercise subjects walked more efficiently, while the control subjects showed no change. The study concluded that regular exercise could improve movement economy.

Exercise studies have shown that *judicious* exercise can improve muscle strength, range of motion, cardiorespiratory fitness, and efficiency of movement in some post-polio individuals. These benefits appear to occur when they keep their activity and exercise within reasonable limits to avoid excessive muscular fatigue or joint or muscle pain. Post-polio individuals should avoid activities that cause increasing muscle or joint pain or excessive fatigue, either during or after their exercise program because the performance of activity at too high a level may lead to overuse/overwork problems.

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2000 Paralympic Games – Archery Update

Our Internet Webmaster Tony Marturano recently sent me an update on his preparation for the Paralympic Archery event. He writes:

> *I am now ranked equal 6th on the World Ranking list and have also come third in the able-bodied State Championships, with fellow archer in the Paralympic Squad, Arthur Fisk, coming second (he is also ranked 8th on the World Ranking list). I am now shooting from a chair which has given me a lot more stability and I hope to be number 1 by the time of the Paralympics.*

The Archery Sport Division of the Sydney Organising Committee for the Olympic Games (SOCOG) is seeking **volunteers** to assist with the conduct of the Archery event at the Paralympic Games (Training and Practice: 11-19 Oct, Competition: 20-25 Oct). You don't require any knowledge of archery – training will be provided. All you need is a willingness to become part of a wonderful sporting event, and hopefully see the Australian Paralympic Archery Squad take the Gold. If you or any of your family or friends can help, please contact James Larven at SOCOG on (02) 9297 3704.

Polio Particles

Mary Westbrook

Polio Particles is compiled by Mary Westbrook as items on polio or post-polio 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, and other items of interest.

A Polio By Any Other Name

One of the aims of the disability rights movement has been to do away with disabling language. A common example of such language is describing a person as if they are their disability eg when nurses refer to the gall bladder in the bed near the window and the fractured femur by the door. In many health professions' journals it is now mandatory to refer to "people with arthritis" etc rather than to arthritics. Yet many people who had (or I sometimes wonder if it is more accurate to say have?) polio still like to refer to themselves as polios. In the March/April 1999 issue of the American magazine *Disability Rag* Sally Rosenthal (who is not a polio) wrote, "While I generally dislike describing oneself in terms of a disability, I have come to see the absolute relevance of it in relationship to polio. The social phenomenon of the experience really does shape and define this subculture. People who call themselves 'polios' are I think, reflecting pride, like Vietnam vets do, in having been through a type of battle that will never occur again in this country. People who use it want to be remembered as its veterans."

(*Ed. This helps explain why our Network polio virus badges are selling like hotcakes. The badges feature a striking four-colour design and are still available at $5 each plus $1 postage – order yours today!*)

Polio Stories for Grandchildren

Recently the Network received a request from a woman whose mother who had been a Network member prior to her death. The daughter was attempting to write a family history for her own children but was hampered by her lack of knowledge of her mother's experiences with polio. The mother would rarely speak about it. The daughter believes her mother's reticence was caused by her shame at having a disability whereas she considers that her mother's story would be a source of pride and inspiration for her grandchildren. We were able to put her in touch with four Network members who contracted polio about the same time as her mother, in 1916, and who were pleased to share their memories. A good way to open the way to talking about polio to children is via other people's published stories. One such book, for children aged around 9-12, is *Small Steps: The Year I Got Polio* by Peg Kehret (published by Albert Whiteman & Co, Illinois, 1996). Kehret, award-winning author of many children's books, writes about her hospitalisation with a severe attack of polio when she was 12 years old. She describes the isolation ward, her treatment, and her eventual return to school using walking sticks. A final chapter tells what happened to the children in her ward and her realisation 40 years later that, "the enemy was not vanquished but had merely gone under cover, waiting to strike once more. My battle with polio is not yet over. When my doctor recommended physical therapy, I burst out laughing. Here it comes, I thought. The Return of Torture Time."

In the prologue Kehret writes that her hospitalisation with polio, "more than any other time of my life molded my personality". Her story may differ from yours but that makes a good casting off point for talking to the grandkids. I have seen Kehret's book at the *Feminist*

Bookshop at Lilyfield. It is also available from Internet bookstores. For example, *www.amazon.com* has the book in hardback for $US10.47 and paperback for $US4.76 plus packaging. You can pay by Visa, Diners Card or American Express).

What Other Polios Think

An interesting Internet site (http://angus.skally.net/ppsc/) is *Post Polio Central*. You can have your say in a bi-weekly poll and read the results of previous polls, which were completed by the 200 or so polio survivors who visited the site that fortnight. The diversity of survivors' experiences is revealed in answers to questions, some of which are shown below.

- *Do you feel that the emotional toll that the original polio took is*: Less than the physical toll (45.5% agreed), greater than the physical toll (30.3%) or equal to the physical toll (24.1%)?
- *Do you think, in general, medical professionals understand PPS?* No (53.6%), very little (25.7%), somewhat (17.5%), yes (3%).
- *Has increased disability put a strain on any of your relationships?* Yes, some (50%), yes, a great deal (30.2%), no (11.6%), yes, very little (8.1%).
- *If you knew soon after recovering from polio what you do now about PPS would you* have lived your life the same (48.6%), have done less (27%) or done more (24.3%)?
- *Has an understanding of PPS and its causes led you to modify your way of living?* Yes and the changes have helped my symptoms (71.6%), yes and the changes have not helped my symptoms (23.4%), no (4.9%).
- *What is the primary challenge, for you, of living with PPS?* New and/or increasing physical limitations (35.5%), fatigue (17.7%), pain (11.8%), fear/anxiety (4.2%), depression (2.5%), none of the above (3.3%), all of the above (21.1%).

A Paralyzing Fear: The Book

For those who missed the film or enjoyed the film but want more details of the story (including the late effects of polio) the book by Nina Gilden Seavey, Jane Smith and Paul Wagner was published by TVBooks, New York in 1998. It is 288 pages in length and contains over 240 pictures. You can purchase it from the Internet bookstore *www.amazon.com* for $US22.46 (about $A35) plus postage or you can request your local library to purchase a copy. The video is available for about $90 but I found the book more informative and satisfying.

How Polio Vaccines Work

The Network receives many queries from members and from people in other countries who e-mail our Internet site (*www.post-polionetwork.org.au*). A recent question asked, "Regarding polio immunisation, do the antibodies formed remain for life or for a period of time, and can they be identified in the lab?" We asked Dr Marcia Falconer, a biologist in Ottawa, for an answer. Dr Falconer has conducted extensive research in virology and molecular biology and has published several papers on the late effects of polio. Dr Falconer is a polio survivor and as she visits family in Sydney we are hoping she will present a seminar for the Network in the future. This was her answer to the query on vaccines:

There are two types of polio vaccine, live vaccine and killed vaccine. The easiest to understand is the Salk, or killed vaccine. In it, the three types of polio virus strains, pv1, pv2 and pv3 are killed by exposure to a chemical, usually glutaraldehyde. This completely inactivates the virus so that it cannot infect cells. However when it is given, usually as an injection, the cells of the immune system in the body recognise the dead virus as an "invader" and form antibodies. They will form antibodies to all three types of virus since the virus strains have slightly different shapes and the antibodies react to this shape to produce different antibodies. The body will produce antibodies to all three types, but it will not produce equal amounts of antibodies to each. Usually it produces higher antibody levels to types 1 and 2 and lower levels to type 3. This probably has to do with the actual shape of the virus (the antigen). However, the levels produced are sufficient that any subsequent infection with live virus of any, or all, of the three polio virus strains will be held in check and the person will not go on to develop paralytic polio.

The Sabin, or live vaccine, is quite different. Researchers spent many years finding a variety of each strain of poliovirus, pv1, pv2 and pv3, that would not attack the nervous system. These are called "attenuated" viruses. It means that, theoretically, a person can be infected with these attenuated viruses and they will not develop acute polio, but they will produce antibodies to these viruses and the antibodies will be effective in preventing any subsequent infection by the "real" (not attenuated) polio virus strains. That is the theory. What happens is this... A person is given the "live" (attenuated) vaccine by mouth. Usually the vaccine is dropped onto a sugar cube and this is eaten. The three attenuated strains go through the stomach into the digestive system where the virus can attach to certain cells of the intestine. This is the route of infection for real or "wild type" polio virus (the unattenuated, naturally occurring polio virus strains). However, once the virus in the vaccine enters into the blood stream, it stops there. It will not enter the nerves. Instead the immune system kicks in and makes antibodies, which destroy these viruses. These antibodies remain, at some level, in the blood and will protect the person from a later infection with the real, wild-type polio virus.

With both vaccines, the level of antibodies produced varies from person to person. The antibodies, and the capability to make MORE identical antibodies, remains with the person, usually for life. Thus they say that the oral, or "live" or Sabin vaccine will confer life long immunity to polio. However, in some very small number of people, the live, attenuated virus that is used in the Sabin vaccine to produce antibodies, will mutate. These mutated viruses are capable of both reproducing themselves (eg infecting other cells) AND are capable of attacking the nerve cells. In some people their bodies have already begun producing antibodies and so the mutated viruses don't survive long enough to do any damage to the nerves. However there will still be live viruses, infective ones capable of causing paralysis in a susceptible person, which are shed in the faeces. Thus an infant may not come down with acute polio but will shed wild-type, infectious polio virus in the faeces and parents or others who diaper the child are then at risk, if they haven't been immunised, of getting paralytic polio. In some unfortunate cases, the mutation occurs very early, shortly after the vaccine was ingested. The body does not have time to make antibodies and so the virus gets a foothold and the result is vaccine-caused paralytic polio.

There is, however, a perfectly safe way to immunise people, one that protects both the child and the parents. You first give the child injections of the killed, Salk, vaccine. After the child has produced antibodies, usually 6 months or so later, you then administer the live, Sabin, vaccine. When you give the first shots, you must also ascertain that everyone around the child has up to date immunisations - or give them shots as well. The administration of the dead vaccine produces sufficient immunity so that when you give the "live" vaccine later on, the antibodies are already present. The reason for giving both types, sequentially, is to prevent vaccine-caused polio. You could give only the shots of

the "dead" vaccine, but this usually doesn't confer life-long immunity and regular booster shots are required. The live vaccine, does, normally, give sufficient immunity to protect you from polio for the rest of your life.

Ed. Currently, Australia's immunisation schedule recommends the Sabin vaccine except for immunocompromised persons. Readers may be interested to know the situation in the USA where The Center for Disease Control and Prevention's *Morbidity and Mortality Weekly Report*, 1999, 48, 12-16 advises in part: *As a result of progress in the global eradication of poliomyelitis, the need for further reductions in the risk for acquiring vaccine-associated paralytic polio, and the acceptance of inactivated poliovirus vaccine (IPV) by parents and physicians, the Advisory Committee on Immunisation Practices (ACIP), the American Academy of Family Physicians (AAFP), and the American Academy of Pediatrics (AAP) recommend IPV for the first two doses of poliovirus vaccine for routine childhood vaccination. The ACIP continues to recommend a sequential schedule of two doses of IPV administered at ages 2 and 4 months, followed by two doses of oral poliovirus vaccine (OPV) at ages 12-18 months and 4-6 years. The administration of IPV for all four poliovirus vaccine doses also is acceptable and is recommended for immunocompromised persons and their household contacts. OPV is no longer recommended for the first two doses of the schedule and is acceptable only for special circumstances (e.g., vaccination of children whose parents do not accept the recommended sequential schedule, late initiation of vaccination that would require an unacceptable number of injections, and imminent travel to countries where polio is endemic.) OPV remains the vaccine of choice for mass vaccination campaigns to control outbreaks of wild poliovirus.*

Support Group Report

Neil von Schill **Phone: (02) 6025 6129**
Support Group Co-ordinator

As I am just settling into this role, this initial Report is somewhat brief. I have now contacted all Conveners and will be reporting on the progress and activities of Groups in upcoming Reports.

May I take this opportunity of thanking members for the opportunity to serve the Network as Support Group Co-ordinator for 2000. I am looking forward to meeting many Conveners and members at meetings and seminars in the months to come.

My attendance at the *Polio 2000* Conference held in Melbourne in January highlighted for me how each of the state networks has evolved in its own individual way and no two are alike. The NSW Post-Polio Network is unique in that we are an independent organisation, free to develop our own policies with our Support Groups being governed by the Constitution and administered by the Management Committee.

We must realise also that belonging to a Support Group is *a* choice that each member has, depending on the availability and accessibility of a Support Group in the local area and of an individual's needs at a particular point in time. Some members do not feel the necessity to belong to a Support Group because their needs are being met by the existing support provided by our excellent publications, the quarterly *Newsletter* and *Information Bulletin*.

As members' needs change, our network of Support Groups is available to provide personal or phone contact to meet emerging contingencies of individuals. If members wish to know of the existence of a local Support Group they can contact me at any time.

In Memory Of Oscar

Member Joan Clarke (who publishes as Joan Willmott-Clarke) sent me this delightful account of her travels with her scooter Oscar. The piece is dedicated to her grandson, Joel Clarke, for his 14th birthday on 30 January 2000.

He was old but still frisky when we first met. I ignored his dints and bruises and he ignored mine. It was love at first sight.

I was living at Byron Bay then and after breaking my polio leg was forced to rely on crutches to get around, so I lost no time in mounting Oscar, whose only protests were a few tinny grumbles, but when I carefully headed him out through the gate towards the park he responded with alacrity. It was a week day, school was in and there were no football or cricket teams to threaten us. The path that led through the park to the town road was deserted. With no traffic and a crisp breeze to cool the sun's heat, I coaxed Oscar to increase his speed. The birds picking in the dirt and dust flew off bewildered; a couple of cats squealed and turned tail, while dogs heading towards us suddenly stopped and stood rigid with ears stiff and upright.

I was soon to realise that it was Oscar's soft whine that unsettled the animals. They could hear it long before we approached them.

The road up to Byron Bay's shops seemed too rough so I kept Oscar on the footpath, rough as that was with broken kerbing and ramps on our side of the road and long grass on the other side. Difficult as our progress was, though tough on Oscar, it was better for me than struggling on crutches over such terrain. Soon, ignoring the bumps, we quickened our pace. As we passed the well-mowed bowling green, the bowlers paused and waved to us. "Take it easy, love!" one called to me. "Don't let the coppers catch you speeding." "I won't!" I shouted back, as an excited Oscar bumped over the broken kerbs.

Dear old Oscar! For months he took me everywhere, to coffee shops, restaurants, and down to the Byron Hotel overlooking the ocean. He was a bit clumsy at first, entering a coffee shop and knocking over chairs and tables, then having difficulty in turning around and getting out of the shop, but most shopkeepers were very tolerant, sometimes laughing as they lifted Oscar with me on top of him and turned us around clear of their furniture and facing the door.

We were both contrite as we slowly made our way out of the shop. Oscar was a big bloke. I doubt that he had ever been nimble, even when young. Now at whatever ancient age he was, his furrows and creases were becoming more conspicuous.

He had always been very fond of children and they of him. They would follow him around, pat him, try to mount him, talk to him and ask me questions about him. My own grandsons, then quite young, knowing they were not allowed to get on him, would run by Oscar's side, challenging me. "Go on, Nanna Joan. Go faster. Go on!" I don't think Oscar enjoyed those challenges, and they scared me too.

Maybe his eyesight was deteriorating for he was most clumsy in the Supermarket, knocking packages off shelves and tipping over stands in the aisles. But when we headed for home he needed little help from me to find his way there. On the porch I would connect him to his sustenance and when he was finished, I would cover him and say goodnight.

Than one day our happy journeys were interrupted. I had to go to hospital. I had broken my polio leg. Eventually I was flown to Sydney for an operation and had to leave Oscar

with my son. I don't think he liked that, nor did I. We had become very close to one another. A few months later, the operation over, the hospital surgeon said I could leave but was not to walk any long distances yet. He recommended that I use a wheelchair but when I told him about Oscar he agreed that I could use him instead.

There was great excitement when Oscar arrived at the hospital. All the nurses wanted a ride on him. Everyone thought he was beautiful. Oscar wallowed in their admiration. I was allowed to ride him in a safe space, but was warned not to let him loose around hospital staff, patients or visitors. When I left for a stay in a hostel, he came too but to our mutual sorrow, Oscar was relegated to a back yard with no protection from the elements. What was most disturbing was that I could not get to him.

I moved on from that hostel, trying out a number of others. In the ones in which he was welcome, the terrain was too difficult for me, or there were too many fast cars. Then I moved to Manly, lovely Manly, where I had lived with my parents during the war years. What fun we had there! I would ride Oscar along the ocean front, then down to the harbour. As I rode him down past the Manly pool where I used to swim, and onto the wharf to watch the ferries berth and leave again, I would tell Oscar stories of travelling on those ferries in the blackouts at night, with the ferry musicians playing "When the lights come on again", an English wartime song. Or I would tell him what it was like to go for a ride on the Ferris wheel where at the top you felt you could almost touch the stars. Oscar was a good listener, never interrupting.

Some days we would go for coffee on the Corso. The shopkeepers never resented his presence at their outside tables and would rush to move chairs out of his way. Then came the day when builders started digging up roads and footpaths. Getting around was no fun, unless we stuck to the Corso. Small children loved him and would race up to ride him sitting in front of me. Oscar was very gentle with them, moving slowly and being careful to avoid the bumps. But I was finding it difficult to ride him over the broken roads and footpaths. One day we both nearly had a bad fall. I knew his time was almost up. But first the local newspaper wanted to take his photo with me riding him. That really was our last ride together.

It was very painful having to part with him but a man bought him and promised to be kind to him. The last I heard was that he was enjoying the fresh air and open spaces of country life.

To replace him I bought the "Rascal", a frisky little devil, younger and smaller than Oscar, and very fast. A "show-off". If I don't control him, he'll tip me off, run into a restaurant or even people without stopping to apologise. Guess I'll learn to control him one day. He's a clever little scooter but I doubt he'll ever be as faithful as my first scooter, dear old Oscar.

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Our **mid-year Seminar** will be held on **Saturday 8 July 2000**, at **St Paul's Anglican Church Hall, Kogarah**. **Dr Katrak, Rehabilitation Specialist, Prince Henry Hospital**, has agreed to talk to us about what he learnt at the March of Dimes Conference at Warm Springs, Georgia, USA, being held in May for researchers of post-polio syndrome. Attendance at the Conference is by invitation only and we expect that the leading experts on post-polio will be there. The Network requested that Dr Katrak receive an invitation because of the importance of Australian polio survivors having access to the latest information about post polio. You won't want to miss this Seminar so make sure the date is marked in your diary now.

Don't Miss This Chance to Meet with old Polio Friends

Some of you may have seen the following item feature in *Column 8* of *The Sydney Morning Herald* on 26 January:

> *Former Sydney lord mayor Doug Sutherland has no trouble remembering Australia Day, 1950. It was the day the then teenager was admitted to Ward B1, the polio ward, at Prince Henry Hospital. He spent exactly one year there. making many friends among fellow patients. He is organising a reunion for Ward B1's patients and medical staff of 1950.*

Doug has received many calls not only from patients and staff of Prince Henry in 1950, but also from other hospitals and other years. Because of the interest his item generated he has decided to broaden the scope of the reunion to include anyone interested in getting together. In conjunction with the Network, a *Reunion Organising Committee* has been formed to work out the details of the reunion (planned to be held later this year). If you would like to join this great celebration and catch up with people you may not have seen for fifty years, please contact Doug on (02) 9747 2055 (b.h.) or Merle on (02) 4758 6637. **We are also asking the interstate Networks/Support Groups to help publicise the reunion to their members.**

Poet's Corner

I had the pleasure of meeting new member Joan Thomson from Mullumbimby at the Polio 2000 Conference in Melbourne. She delighted participants with an impromptu reading of this poem, and has generously given permission for us to reproduce it here.

My Wonderful Obsession

Each morning at sunrise the cravings begin,
My body is telling me it's time to jump in.

I shower and dress, nothing else on my mind
I warm up the car – my batteries are buzzing,
Meeting up with my mate, we're two of a kind,
A driving desire to make it to Byron in time.

It's already eight-thirty, will we make it,
Jump in the deep end, line up with Barry and Janet.
The music is starting, the teacher speaks forth,
Oh, what a giggle, Bob's just lost his shorts.

Summer and winter my passion survives,
Rain, hail or storm,
My love for Aqua-aerobics is just fine.

We use buoyancy belts, dumbbells and floaties,
And have so much clean fun.
For few are so friendly, so joyful and sexy
As a long purple woggle stuck around and under your bum.

Later while resting in the luxury spa, white and frothy,
One dreams of Sean Connery, holding hands and drinking bubbly.
Telling me I'm beautiful, charming and slender,
Taking me to his ranch, in far away splendour.

But what will he think of my wonderful obsession?

Up in the morning, drive down the street, batteries are firing,
I just can't live without Aqua-aerobics,
Which has turned my whole life about.

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Thank you to those thoughtful members who sent greetings and messages of support to the hard-working Committee at Christmas – we appreciate your encouragement. Regular correspondent Ruth Crowder of Nambucca Heads included the following in her card.

This is a light-hearted observation from someone who has taken up being a wheelie rather late in life.

Why do people invariably stand behind the person they are talking to, who happens to be in a wheelchair? Is it because the back of our heads are easier on the eye than our faces? Not only do I end up with a stiff neck but a bad dose of frustration.

I have taken up SLOTH, thanks to your advice and am much better for it. I am working on it and feel it should be on the *Sport and Leisure* pages of *The Sydney Morning Herald* !

Long-time member Yvonne Stone recently wrote to me about her move into an aged-care hostel on NSW's North Coast. Despite her initial fears, she is doing very well. She writes in part:

I dreaded having to move, my main worry was would I be able to keep warm as I knew hotties would not be allowed. Wheat bags are, but I never need mine as I am given a hot foot spa and massaged with Evening Primrose Oil before bed every night. Also full spa and massage once a week. We are all treated for our individual needs. The Aged Assessment Team said I am too disabled for a hostel, but fortunately the Nursing Manager decided to give me a trial and although I am a high care patient it has worked out wonderfully. The staff (carers) are all wonderful, I have my own room, pictures, furniture etc with toilet, shower etc, my budgie, TV etc. The food is great and my allergies to gluten and lactose catered for.

Some of the staff are taking a great interest in polio and post polio. So the Newsletter before last was really helpful. So I can do what I can, and ask for help when needed, encouraged without being pushed. And treated with more understanding than ever before. I have been here seven months and love it all. Needless to say there is a long waiting list.

The consensus of opinion from participants attending the Polio 2000 Conference *in Melbourne in January was that it was an experience not to be missed. The letter I received from member Norma Hinde the following week summed up why it was so important that the Conference went ahead, and why it was so necessary to pull out all stops to get it back on track after Paraquad Victoria pulled out. It was very gratifying to receive this positive feedback.*

Dear Gillian

If you had not got on the phone and said "They cannot do that to us!" I would not now be looking back on the wonderful and extremely valuable experience we had in Melbourne last week. There were so many good speakers and so much valuable information that it will take me some time to digest it all.

As you know, we have only belonged to the Network for the last couple of years, so meeting others with similar problems and having the opportunity to discuss experiences was a very important part for me. Also I have learned a lot about resources which could help me, so do not be surprised if you find me ringing you to ask what is available in Sydney. I have already got a letter from my doctor to start hydrotherapy at RNS Hospital.

So thank you so much for getting this conference back on the road and for all the effort you put into making it such a success.

Warmest regards, yours sincerely

Norma Hinde