



POST - POLIO NETWORK (NSW) INC.

NETWORK NEWS

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President's Corner

Gillian Thomas

Welcome to regular readers and new members to another bumper issue of *Network News*.

I am very pleased to report that the Mini-Conference held on 18 May was a great success, attracting more than 100 attendees. Read a preliminary report on the Mini-Conference and the Support Group Convenors' Workshop on page 6.

Our Raffle in support of this and future conferences was also very successful, and brought in funds of over \$4,700. The Raffle was drawn at the Mini-Conference and you'll find details of the prizes and lucky winners on page 22. Our sincere thanks to everyone who supported the Raffle, and to those who made donations totalling nearly \$3,000 in support of our conference programs.

Several years ago Mary Westbrook investigated the strategies Australians with late effects from polio use to cope with their post-polio problems. She looked at the lifestyle changes, personal and social strategies survivors use and how helpful they have found them to be. Considerable research has shown that having support from others significantly reduces the stress people experience in difficult life situations. Margaret Campbell found this was true of women with severe late effects of polio. Those with supportive families were much less depressed and more accepting of their disabilities than were women who lacked support. Mary found that survivors are extremely reluctant to ask for help. Only 39% of the polios in her survey had ever asked family members for practical help and 19% had asked friends for help. When they did ask for help only just over half of those who did so found it very helpful. More survivors were able to talk about their post-polio problems; 75% had talked with family and 74% with friends. However the majority of those that talked did not find it helped them very much. Only 39% who talked to family and a mere 19% who spoke to friends said it was very helpful. Mary wrote that "Factors contributing to survivors' reluctance to talk about their disability include a strong social taboo about discussing one's disability and the discomfort such talk arouses in others. Most survivors were hospitalised for long periods of time when they contracted polio. Children were usually only permitted one visit each week. Exposure to isolation wards, paralysis, pain, frightening procedures and equipment, and care administered by distant and at times abusive staff has left many survivors with profound, though often unacknowledged, fears of abandonment. They tend to display a false self sufficiency and have little empathy for themselves. Many survivors require help to increase the social support in their lives". Our upcoming Seminar on 31 August hopes to provide such help. See page 2 for more details.

The back page of this *Network News* again highlights this year's upcoming activities. Please note the dates in your diaries. You will see that we are holding two social events this year. First there is a play *Murder in the Sydney Opera House* on 3 August (see enclosed flyer). Second, we are holding a reunion of polio survivors and hospital nurses. Whatever hospital you were in, you are most welcome to attend this reunion luncheon on 25 October at the Burwood RSL. For \$25 you will enjoy a buffet lunch and a rare opportunity to swap stories about your polio days. Invitations will be sent out early in September. Please call Doug Sutherland on (02) 9747 2055 for more information.

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Living with Polio – A Family Affair

A seminar for you **AND** the important people in your life

Date: Saturday 31 August 2002

Time: 1:00 pm - 3:00 pm *followed by afternoon tea*

Bring a packed lunch to eat from 12:00 noon

Fruit juice, tea and coffee will be provided

Venue: The Northcott Society

2 Grose Street, Parramatta

Ample parking is available in the Parramatta Leagues Club 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.

If you are travelling by public transport, you can catch Bus 600 from Parramatta Railway Station to the Leagues Club.

Adam McLean, Counselling Co-ordinator of Carers NSW Inc, is our guest presenter. Adam's talk will help us all to understand how polio's late effects can influence our relationships. Reduced mobility and increasing difficulty with undertaking normal daily tasks can be hard for all family members, not only the polio survivor, to come to terms with. Denial that it is happening is not the answer. Adam will explore issues such as breaking the silence, loss and anxiety that surrounds polio survivors, their partners and family members as they experience the impact of change for themselves and their relationships. As usual, the Seminar will have an interactive format – questions and discussion are welcome and encouraged.

As Dr Mary Westbrook, Seminar Co-ordinator, puts it: "This Seminar is for members **AND** for those who care for and about them. The Seminar aims at increasing understanding and improving communication - it will help both groups gain a heightened appreciation of each other's viewpoints and problems. Issues that are difficult to talk about will be aired and new, and sometimes surprising, insights will be gained by both groups."

Committee Member Anne Buchanan is married to a polio survivor. She says: "Being a member of Carers NSW Inc I am pleased to see that Adam McLean will be the speaker at our August seminar. I have, in fact, completed a course conducted by Adam on behalf of Carers, and certainly found it most beneficial. I hope that polio survivors and their families alike will take this opportunity to come along and learn more about each other."

We look forward to seeing everyone there. If this is the first Seminar you have attended, please be sure to introduce yourself to a Committee member. Don't forget that afternoon tea after the Seminar is a great opportunity to catch up with friends.

Dr Henry Writes ...

Henry Holland MD, is a polio survivor, a board certified psychiatrist and an associate clinical professor of psychiatry at the Medical College of Virginia who has led the Central Virginia PPS (Post-Polio Syndrome) Support Group for some years.

A series of Dr Holland's articles appears on the Internet on the Lincolnshire Post-Polio Network's Web site www.ott.zynet.co.uk/polio/lincolnshire/ under the title "Dr Henry Writes ...". Dr Holland has generously given us permission to reproduce his articles in our Newsletter. Dr Holland's permission must be sought to reprint any items published in this series; he can be contacted by email at Henry4FDR@aol.com.

The following article was originally published in the Central Virginia PPS Support Group's newsletter The Deja View in January 1999. Dr Holland's thoughts on polio spouses are particularly relevant considering the topic of our Seminar on 31 August. We hope that many polio spouses will come along to the Seminar to hear our speaker's insights – remember, the Network exists not only for polio survivors but also for those who care for and about them.

Dr Henry writes about Polio Spouses

Henry Holland MD

Richmond, Virginia, USA

January 1999

Eleanor Roosevelt is probably the most famous polio spouse of this century. She was born into an aristocratic family on November 7, 1884. However, emotional losses and low self-esteem plagued her developmental years. She was the oldest child and only daughter of Elliott Roosevelt, President Theodore Roosevelt's brother, and his beautiful and vivacious wife, Anna Livingston Ludlow Hall. At age two and a half, she was crossing the Atlantic with her parents when their ship was involved in a collision. The terror of being lowered from on high to a lifeboat left her with a fear of heights and the water. As a young child, her mother called her "Granny" because she was so serious and mature. When she was six, her mother said, "You have no looks, so see to it that you have good manners". As a result, Eleanor tried to be dutiful, compliant, obedient, responsible, and useful, but she was also independent, goal directed, and willful.

Death left her an orphan by age ten. She had two younger brothers. One of them, Elliott, died at age four from scarlet fever. When she was eight, her mother died from diphtheria. Her father had a history of alcoholism and chronic depression. He was not awarded custody of Eleanor after her mother's death. Eleanor went to live with her maternal grandmother in Manhattan. Two years later, her father died from the consequences of alcoholism. She stayed with her grandmother for seven years. During this time, she grew to be a tall, but rather awkward and self-conscious teenager. She was a loner and an outsider. At the age of fifteen, her grandmother sent her to the Allenswood boarding school in England. At this school, Eleanor came under the influence of the headmistress, Mademoiselle Marie Souvestre. This school was most progressive for the Victorian nineties. The daughters of England's more liberal leaders attended this school. Eleanor excelled at Allenswood for three years. She became more self confident, versatile, and a well loved young woman. At age eighteen, she returned to New York, involved herself in social work causes, made her debut in society at her grandmother's insistence, and soon met Franklin.

In August 1921, she became a polio spouse. During her husband's acute illness, she was his bedside nurse and performed many necessary duties such as attending to his urinary catheterizations. Over the next several years, despite her mother in law's opposition, she kept the hope alive in Franklin's mind that he could return to politics. Franklin did become the four times elected President of the United States. During this time, Eleanor became his conscience, promoting progressive social reform. She became his legs and traveled throughout the world as his "ambassador of hope". She was a person ahead of her time. She was a feminist. She was compassionate and idealistic. She was a friend to the disenfranchised. She was an assertive and hopeful voice for the hungry, the unemployed, and African Americans. She became a writer, a teacher, lecturer, and voluntary ambassador.

When asked about her husband's polio, she would say his polio was a "blessing in disguise". Some had argued that FDR had always been a powerful and compassionate man; she believed that Franklin's struggle with polio "gave him a strength and courage he had not had before. He had to think out the fundamentals of living and learn the greatest of all lessons - infinite patience and never ending persistence".

Eleanor appeared on the Edward R Murrow TV Show, "This I Believe". In response to a question about her life, she stated, "You have to accept whatever comes, and the only important thing is that you meet it with courage and with the best you have to give".

In my opinion, Eleanor Roosevelt's perceptions as a polio spouse are astute and wise. As polio survivors, most of us learned long ago about the value of patience, persistence, and trying to think through the fundamentals of living. For many of us, polio brought a precocious understanding of the perils of life. If we did not learn and exercise these lessons years ago, we certainly need to exercise them now with the realities of Post-Polio Syndrome (PPS).

There are a number of polio spouses who are quite active in our post-polio support group. From my observation, these spouses fully represent individuals who have learned "to accept whatever comes" and have met adversity with "courage and the best they have to give". No marriage is all bliss and joy. The realities of polio and now PPS can stress the best of marriages. Based on last year's survey of our group, 70% of our members are married. 51% felt that the development of PPS had had some impact on their families. The changes that might result in a marriage relationship as a result of PPS can be adverse, or can be part of the "for better or worse, in sickness and in health" definition of a committed marriage.

I think that polio spouses are often forgotten and overlooked heroes. For many of us, they are "gofers". They run errands, pick up things, and help with many details of daily living. They also get tired and moody, and have bodily aches and pains. Usually, they say "yes" more often than "no" to us, are our thoughtful personal advocates, and our loving protectors. Marriage relationships are traditionally complementary, as each spouse is expected to manage certain tasks toward the maintenance of a home and the raising of children. The invasion of PPS may alter the dynamics of that complement. As a consequence, the polio spouse may feel somewhat abandoned, needed more than loved, and less valued. This is more likely to occur when the PPSer is having greater difficulty accepting and adjusting to a life with PPS. When the PPSer is more anxious, fearful, depressed and uncommunicative, the polio spouse may be on the receiving end of irritability, complaining, and subtle rejection. Both marriage partners may well understand this process, but feel helpless in changing it. Meaningful communication is the key to working through the changes that have occurred and in establishing a new and lasting complementary relationship. If this level of communication is not possible, professional help may be an excellent next step.

As a first lady, Eleanor Roosevelt made a positive impact on the lives of many people. As a polio spouse, she must have felt the anger, fear, and uncertainty brought to their lives by her husband's polio. I feel that many polio spouses have felt and may still feel the anger, fear, and uncertainty that PPS has brought. There may be no brilliant dynamic psychotherapeutic models to resolve the realities of the impact of PPS on a marriage. Eleanor's advice is the best that I have heard.

"You have to accept whatever comes, and the only important thing is that you meet it with courage and with the best you have to give".



Cross-Cultural Study of Sleep in Survivors of Polio

Dr Elizabeth Ellis

The University of Sydney, School of Physiotherapy, is very grateful to the Post-Polio Network (NSW) for its cooperation in this first ever cross-cultural study of the sleep profiles of survivors of poliomyelitis in Australia, Canada and New Zealand. The research project looked at the history of poliomyelitis as well as the current day time function and sleep patterns in people who have had polio. Sleep patterns were investigated because they are essential to being able to function well in the day, as well as to general well being and overall health. Five hundred members of the Post-Polio Network were sent a questionnaire and asked to volunteer to complete it. Ninety-six pairs of responses were matched for age and sex and used for this initial analysis. At the Network's Seminar on 2 March 2002, the following findings were presented.

Research Questions and Answers

What is the incidence of disturbed sleep in people with PPS? And is this different to the normal population matched for age and sex? The proportion of people classified as having sleep disturbances was greater in people who had survived poliomyelitis (26%) than in the control group (15%).

What proportion of the disturbed sleep is caused by breathing disorders? The proportion of people classified as having sleep disturbances who also had evidence of breathing problems during sleep was greater in the people who had survived poliomyelitis (20%) than in the control group (14%).

What proportion of the breathing disorders could be contributed to by PPS? (ie respiratory muscle dysfunction vs obstructive sleep apnea). More of the polio group reported to having had breathing problems than the control group. However, the proportion of people who had breathing problems, and who had difficulty breathing during sleep, was the same for both groups (4%). In addition, there was no difference between the polio group and the control group on the severity of the symptoms of breathing problems in those that had them. Consequently, less of the sleep disordered breathing could be explained by breathing problems in the polio group than in the control group.

What factors are strong predictors for disorders in sleep caused by PPS? The link between disorders of sleep in polio survivors appears to be more related to their history of polio than any specific compromise of their respiratory system. Sleep studies may be useful in the identification of sleep disordered breathing in subjects displaying evidence of sleep disturbances and would help identify the cause in individuals.

This exciting project is a collaborative effort between Prof Elizabeth Dean in Canada, Margot Skinner in New Zealand and Dr Elizabeth Ellis in Sydney. The survey was managed by Ms Helen Papadopoulos who graduated with Honours from the University of Sydney in May 2002. For further information please ring Elizabeth Ellis on 0411 032 712.

Mini-Conference 18 May 2002



Our Mini-Conference on 18 May was a great success, with more than 100 people in attendance. Members and friends came from all over the Sydney Metropolitan area, and from as far afield as Canberra, Orange, Armidale, Ballina and Albury, north up the coast to Newcastle and south down to Nowra. Dr Pesi Katrak, Rehabilitation Specialist from the Prince Henry Hospital, also joined us.

An especial welcome was extended to interstate visitors: Rebecca Round (Tasmanian Network), Tessa Jupp (Western Australian Network), Jill Pickering (Polio Network Victoria) and Tori Wilckens (Polio Therapy Services and South Australian Network).

Dr Marcia Falconer's four presentations were very well received, and even the most polio-knowledgeable members present learnt something new. A report is under preparation and will appear in the next *Network News*.

Support Group Convenors' Workshop 18 May 2002



Network Convenors at their working lunch. Pictured clockwise around the table (*starting at top left*) are: Dorothy Robinson (Wollongong), Neil von Schill (Albury) (*partly obscured*), Rosalie Kennedy (Northern Rivers), Wendy Chaff (Hunter), Dorothy Schünmann (Shoalhaven), Bernie O'Grady (Blacktown/Blue Mountains), Brian Wilson (ACT), Doug Crocker (Armidale), Eric Sobel (Eastern Suburbs), Liz Lynes (Upper Blue Mountains – *past Convenor*), Bara Tunnington (Central Coast), and Ruth Wyatt (Northside).

Neil von Schill, Support Group Co-ordinator, reports "*At the Mini-Conference in Maroubra in May we held another successful Convenors' Workshop during the luncheon break with a dozen convenors in attendance from the north, central and southern parts of the state as well as the metropolitan area. It was a worthwhile gathering with a very useful exchange of ideas. May I thank all Convenors for their contribution and for making the effort to attend.*"

To Reap the Rewards of Post-Polio Exercise

Sunny Roller, MA

**Polio Survivor, Program Manager
University of Michigan Health System**

and

Frederick M Maynard, MD

**UP Rehabilitation Medicine Associates, PC
Marquette, Michigan**

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In this year, 2002, we know more about exercise for persons who had polio than we did fifteen years ago. There have been a variety of studies conducted by superb and caring scientists, along with numerous personal accounts from polio survivors themselves, which warrant a new way of thinking about exercise.

Exercise is different than physical activity. For the purposes of this article on exercise, it may be helpful to define these two terms. Exercise is generally defined as planned, structured and repetitive bodily movement, whereas physical activity is the movement you do throughout the day. Physical activity does increase the amount of calories you burn, but unlike exercise, is not necessarily planned, structured or repetitive motion. One benefit of exercise can be an improved ability to take part in ongoing daily physical activity.

Whether you have a planned exercise program or simply rely on day to day physical activity to stay fit, the message to polio survivors today is "beware of inactivity!" In the 1980s polio survivors across the nation heard and heeded a strong medical warning about the dangers of doing exercise, especially too much exercise and/or physical activity, but now post-polio scientists have qualified their advice. New knowledge tells us that no matter what our level of disability is, we should be encouraged to value exercise, enterprising enough to come up with a highly customized plan and enduring enough to reap the rewards. When it comes to exercise, we need to be smart, not scared! One woman in our University of Michigan wellness study told us that in the late 1980s she quit exercising completely out of fear of muscle loss, and gained 35 pounds. Dismayed, she joined the 1996 wellness study to find out what she could do to feel better and it worked! Exercise was put back on her list. She was guided to be selective and conservative as she designed her weekly plan for "working out". She found out that polio survivors need to:

- First, gather the best medical literature from post-polio researchers, educators and clinicians such as Grimby, Agre, Perry, Halstead, Headley, Maynard, Birk, and Yarnell. They will all say that we must each have a custom-tailored plan since we were all affected a little differently by the capricious poliovirus. (See Selected References on Post-Polio Exercise at the end of this paper.)
- Next, find professionals to work with. A well-selected physician and a physical therapist or exercise physiologist who each know or are willing to learn about post-polio issues would be most appropriate. There are no specific formulas for any individual that can be written in an overview article such as this. You must have one-on-one, in-person evaluation and testing to see what works and what does not work for you.

- Then, together, literature in hand, establish a plan for exercise.
- Start slowly, recognize limitations along the way, make adjustments in the weekly activity plan and keep going. Thomas Birk, PhD (1997), recommends a two-month start up period in which your response to exercise is supervised and monitored by the professionals you have chosen to work with.

Gather Literature

The best place to start a literature search on post-polio exercise is to tap the International Polio Network's resources. They have a variety of the latest articles from the best researchers in the world on this very specialized topic. They can be reached by calling 314-534-0475 (*Ed: USA callers*) or connecting with their website at www.post-polio.org.

You may also want to do a literature search of the medical journals at your local library. Librarians can help you do a "Medline search" for pertinent medical publications or you can do one on your own by tapping into the internet, going to www.medscape.com, then clicking on Medline.

Find Professionals

You need to establish an exercise coaching team. This can include you, your physician, and a therapist. If you have a post-polio physician that you trust, he or she is the best person to start with. This physician can then recommend a physical therapist or exercise physiologist to work with as part of your new "exercise coaching team". If you need to first find these professionals, the journey will be longer since knowledgeable post-polio helping professionals can be difficult to find or cultivate. Be encouraged to begin your search however. Remember, if you sense that a professional is not interested in post-polio issues, move quickly on to find someone who will work with you and is willing to learn and help. Once again, the International Polio Network in St Louis, Missouri, can provide you with leads in this search. They publish a national/international directory of self-identified post-polio health professionals and support groups whose members know about the best helping professionals in their geographic area.

Establish a Plan of Action

The experts now agree, when it comes to exercise, a polio survivor doesn't have to do a lot, but one is highly encouraged to do *something!* Once you have gathered your exercise team, decide together what type of exercise is best for you and whether you want to join a group or exercise independently - or both! The amount of physical activity you do will also need to be addressed as you develop this action plan.

Maynard and Headley (1999) emphasize that the main focus of a new exercise program should be on stretching and general aerobic or cardiovascular conditioning exercises to improve endurance. Strengthening exercise, also called resistance training, needs to be approached much more cautiously, however, with a focus on very gradually building up functionally important muscles to a modest degree.

Ann Swartz, PhD (personal communication, February 28, 2002), exercise physiologist at the University of Michigan Health System, describes each of these three types of exercise:

Stretching and Range of Motion Exercise

Why is it important?

Stretching or muscles and joints is important to maximize and maintain function. For instance, arm circles can help maintain the function of your shoulders, making it easier for you to reach for something, or move something out of your way. Preventing tightness in your hips, knees, and ankles will help maximize your walking ability.

What types of exercises are considered stretching or range of motion?

These include arm circles, wrist circles, shoulder shrugs, calf stretches, lifting your knee up towards your chest, bending and extending your knee, knee to chest stretches, back stretches and ankle circles. Many people also enjoy the movements that are part of Yoga or Tai Chi. The following Yoga stretching exercise was part of the University of Michigan *Wellness for Women with Polio Workshop* and was particularly well received:

The Breathing Tree

- Stand or sit erect. Feet apart, body balanced over hips. Arms at sides, palms forward.
- As you inhale raise your arms slowly up. Stretch up, up.
- Exhale arms to starting position.
- Inhale arms to starting position.
- Inhale arms slowly up. Stretch up, up.
- Exhale arms out at shoulder level. Turn head to look at fingertips.
- Exhale twisting from the waist toward the direction you are looking.
- Inhale forward. Turn head to look at other fingertips.
- Exhale twisting from the waist toward the direction you are looking.
- Inhale head forward and arms down to starting position.

Cardiovascular Exercise

Why is it important?

Cardiovascular exercise is also known as aerobic exercise. It is exercise that increases your heart rate and blood flow, and makes you breathe a little more heavily than you would when performing your daily tasks. There are numerous benefits, some you may notice, and some you may not. The benefits you may notice include increased ease of accomplishing your activities of daily living and such things as getting in and out of the car, or going from place to place, and an improved mood. Benefits you may not notice include lower blood pressure levels, improved blood cholesterol levels, and lower blood sugar levels to name a few.

What types of exercises are considered cardiovascular exercise?

Swimming, biking, and walking are examples of cardiovascular exercise. Machines such as the elliptical machines (low impact equipment that combines the movements of walking and stair climbing), stair climbing machines, rowing machines and a machine called the NuStep are also useful for cardiovascular or aerobic exercises. Swimming may be the best exercise for polio survivors because it minimizes mechanical stress on the body. However, you may not have access to a pool, or may not enjoy swimming. So, do what you enjoy, what feels good, and what is accessible.

At what intensity should aerobic exercise be performed?

Health professionals will usually recommend a moderate or low intensity. This means that you should be exercising at a level where your heart rate increases and you are breathing heavier than you would normally (when you are performing your daily tasks). If you cannot easily carry on a conversation, slow it down!

Strength (Resistance) Training

Why is it important?

Strength training, also known as resistance training, improves muscle strength. When your muscles are stronger, it is easier to carry in your groceries, take out the garbage, and other tasks of your daily routine.

What types of exercises are considered resistance or strength?

Any exercises that involve hand-held weights, weight machines, stretch bands, or even balls are usually strength exercises. These types of exercises, like the stretching exercises, can involve any muscle of your body - from your head to your toes.

You may choose to exercise alone or with an “exercise buddy”. Often, sharing the experience with a friend can be more fun, a chance to learn from each other and stay motivated. Joining or starting a wellness program with other polio survivors may also help. Our 1996-1999 study at the University of Michigan (Tate & Leonard, 2001) of a holistic wellness program for women who had polio found that the biggest change was in participants’ exercise routines and resultant physical activity. Program participants changed dramatically in their reported regular participation in vigorous exercise. While prior to their participation 57% never regularly exercised vigorously and 23% did so often or routinely, after their participation, only 26% never did and 41% reported exercising regularly often or routinely. Similarly, program participants demonstrated a marked improvement in terms of the regularity with which they exercised with moderate exertion. Prior to the program’s onset, 63% stated that they did so three or more times per week. Following the program’s conclusion, 78% of program participants reported conducting moderate exercise with this regularity. Also, while prior to the program’s onset 42% of participants said they never engaged in stretching exercises and 23% said that they did routinely, following program participation only 11% said that they never did stretching exercises; 35% of participants said that they did them routinely. Six months following the conclusion of the program, 61% of participants said that they had increased their level of physical activity during the last six months. We also found that exercising vigorously at least three times per week was associated with improved assessments of depression and distress.

Whether with a group or on your own, exercise programs can occur on land or in the water. It is important to do whatever works best for you. If swimming is not possible, you may want to exercise in your house, at a health club or gym, or outdoors. Pick an exercise you enjoy, whether it is walking, stretching, or any other exercise, and begin with small bouts. It is not necessary for you to perform only one activity. You can combine all your favorites. Also, you do not have to do the activity all at once. For instance, Tom enjoys biking, stretching and walking, so his exercise program was as follows:

Morning:

2 minutes stretching
2-5 minute break
2 minutes walking
2-5 minute break
2 minutes stretching
2-5 minute break
2 minutes biking

Afternoon:

2 minutes stretching
2-5 minute break
2 minutes walking
2-5 minute break
2 minutes stretching
2-5 minute break
2 minutes biking

This is how he began his exercise program, and slowly, over the course of months, he began to increase the bouts of exercise and decrease the length of his breaks. It is very important to rest between exercise sessions. Make sure you rest long enough to fully recover after the exercise; otherwise you may remain in a constant state of overload, which has negative effects on function. Incorporating regular rest periods into an exercise routine is called “interval training”.

Exercising in a warm pool is another way to work out. According to Lauro Halstead MD, water therapy was the exercise of choice for many persons during their recovery from the original polio. It is still excellent therapy. Because of the buoyancy of water, it allows people to do things they can't perform on land. For especially weak limbs, inflatable cuffs can be used to float an extremity. For other limbs, water resistance provides a workout that can be fine-tuned to each person's strength. The principal disadvantages of hydrotherapy are that the temperature may not suit one's body and it may be difficult to find pools that have lifts (if needed). Also, the surfaces around pools tend to be slippery and dangerous for anyone with a tendency to fall.

Aquatic programs for exercise have been recognized as morale boosting and physically beneficial. An early study by Hoffman and Maynard (1992) describes a swimming program for polio survivors as having a "therapeutic effect". Emphasizing the added benefit of group exercise, the authors go on to say: "it is of great importance to recognize that perhaps one of the greatest benefits of a program that brings together individuals who share a common concern is the emotional support they receive from knowing they are not alone in their efforts to confront the late effects of polio". In a more recent Swedish study by Willen and Sunnerhagen (2001), 15 persons with polio's late effects worked out in a pool for 40 minutes twice a week for 5 months. At the end of the study, participants reported an increased sense of well being, pain relief and increased physical fitness. Additionally, at the end of the 5-month period, their heart rates during exercise were down. The study's investigators recommend this program of pool exercises in heated water.

In his 1998 book, *Managing Post-Polio: A Guide to Living Well with Post-Polio Syndrome*, Halstead additionally provides general guidelines for customized exercise based on his personal and clinical experience with the effects of polio:

- **Individualized and supervised program.** Exercise programs should be supervised initially by a physician or physical therapist experienced in neuromuscular diseases, if not polio. Each program should be customized to your personal needs and residual strengths. Given these constraints, research studies have shown that some polio survivors (but not all) can improve muscle strength (as a result of new muscle hypertrophy, or enlargement) and enhance cardiovascular endurance with a closely monitored training program. In fact, some studies have reported an increase in strength in muscles both with and without new weakness.
- **Type of exercise.** There are numerous kinds of exercise. Finding the one that is right for you and each of your limbs often takes trial and error. Usually, it is a good idea to find two or more exercises that can be varied, exercising different muscles on alternate days. For example, walking or exercising the lower extremities one day and then performing an upper extremity exercise the next. This kind of schedule provides a period of rest for each muscle group and variation that keeps the overall exercise program challenging and enjoyable. As a general rule, muscles that have a grade of 3 or less (using the muscle examination scale: 0 = no contraction and 5 = normal strength) should be protected and not exercised; grade 3+ muscles can be exercised with caution; grade 4 and 4+ muscles can be exercised moderately; and grade 5 muscles can be exercised vigorously.

Start Slowly; Make Adjustments; Keep Going

It will be important to gradually begin your personalized exercise routine - only do little bits at first. One approach might be to apply the "20% Rule". If you have chosen to do a conditioning program, Stanley Yarnell, MD (1991), post-polio specialist, suggests a general conditioning exercise program to restore stamina or endurance using this "20% Rule". You establish your maximum capacity (the point at which you begin to tire) for any one exercise. Then you begin your program by working at 20% of that maximum exercise capacity. Do

that 3-4 times per week for one month and then increase the rate (time) of exercise by another 10%. Each new month, increase the time exercising by another 10% until maximum capacity is reached. Yarnell clearly warns polio survivors to stop if they become fatigued during their exercise program, or if they experience pain or aches in their muscles. Most survivors, he says, "are able to continue increasing their exercise program to nearly the maximum capacity". Rests are to be taken every few minutes. This 20% Rule can also be applied to home stretching and flexibility programs too.

Halstead also lays out the following guidelines as you begin your exercise program:

- **Expect improvement.** Exercise should make you feel better physically, and even, mentally. If the activity is not strenuous enough to improve your strength, much less your cardiovascular system (eg, stretching or yoga exercises), it still should give you a psychological lift just to be doing a special activity for yourself on a regular basis.
- **Listen to your body.** Avoid pain, fatigue, and weakness. These symptoms are signals that your muscles have overworked. A brief period of fatigue and minor muscle pain for 15 minutes to 30 minutes after exercise is usually normal. Symptoms that last longer than 30 minutes to 60 minutes reflect muscle overwork and possible injury. If this occurs, the exercise should be reduced or stopped. Any exercise that causes additional weakness should be discontinued immediately.
- **Pacing.** Pacing (ie, not going too fast and methodically taking breaks) has been shown to be safe and effective in increasing strength in some individuals. The intervals of exercising can be as short as 2 minutes to 5 minutes alternating with equal intervals of rest. The evidence also shows that secondary symptoms, such as generalized fatigue, can be reduced as individuals become conditioned and are able to perform more work with less expenditure of effort.
- **Use your best muscles.** Polio is often a focal, asymmetric disease with variable amounts of weakness in different limbs. Exercise the limbs least affected or those completely unaffected by polio, while avoiding the more affected extremities. For instance, if only the legs were affected, then the arms can be used in a fairly strenuous program that includes swimming or using an upper extremity arm bicycle; meanwhile, the legs will usually get adequate exercise in the course of doing daily activities.
- **Warm up and cool down.** As with other exercise programs, a warm up (very light movements such as walking slowly, arm circles or leg lifts that are done for about 5 minutes to get your muscles warm, and to get the blood flowing through your body) followed by gentle stretching should be done to improve flexibility and reduce the possibility of injury. After exercising, a cool-down period (very light movements like the warm ups that will slowly decrease heart rate and prevent any feeling of light-headedness that can occur if exercise is stopped abruptly) should take place. Finally, the type of activity should be one that the participant enjoys to minimize the potential for dropping out because of lack of interest.

Having the tenacity to stick with the program and make the proper adjustments is a real challenge, but polio survivors are good at setting goals and achieving them. Across the country men and women who had polio are beginning to apply these principles of exercise and are experiencing much success. The real reason to get into motion is that exercising can make you feel better! Joan Headley (personal communication, February 26, 2002), high profile polio survivor with a mild disability attests to that in her personal account:

In 1994, seven years after I had switched jobs from teaching school (and being on my feet most of the day) to working at the International Polio Network where I consciously stayed off of my feet, several observations caused me to rethink my approach to activity.

The pain in my 'good' leg was gone, but was replaced by a pain in the hip of my 'polio' leg. Shopping trips and other family outings were cut short because I did not have the stamina to be on my feet for more than a couple of hours. Each year it became more difficult to climb the stairs to reach my symphony seat because my legs were weak. Then one night, while walking up those stairs and 'listening to my body', I also realized I was panting and 'out of shape'.

One day an elderly polio physician suggested that the pain in my 'polio' leg was not from muscle weakness, but from connective tissue tightness and perhaps I should 'stretch it'. It was at that point I decided to make a change. I visited Bally's with my brother and sister-in-law and we made the circuit trying each machine identifying my weakest muscles. So, I began an 'exercise' program using Dr Stanley Yarnell's (St Mary's Hospital, San Francisco) 20% Rule. I did a select exercise to the greatest extent I could, and then cut it back to 20% and slowly added repetitions and distance carefully observing if there were any consequences.

Today, eight years later, I have eliminated the pain in my leg by doing 30-35 repetitions at least five times a week, as well as two exercises for my arms. I also walk one mile an average of four times a week and do about an hour of stretching exercises once a month in the pool.

For a few years, I walked in the neighborhood park and an added benefit was that I left all of my daily work problems there. I now walk at the YMCA on an official track with no worry about bumps in sidewalks or my safety when I walk in the evenings. I still leave my problems behind, however - the happily embraced extra benefit of a good exercise program.

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The above monograph quotes extensively from Halstead and Yarnell.

Copies of Dr Lauro Halstead's book *Managing Post-Polio: A Guide to Living Well with Post-Polio Syndrome* are still available from the Network for \$27.50 (including postage and GST).

Members may remember that Dr Stanley Yarnell was a keynote speaker at our 1996 International Conference *Living with the Late Effects of Polio*. Dr Yarnell's paper *The Late Effects of Polio*, which was presented at the Conference, describes the 20% Rule in some detail. Copies of the 170-page *Conference Proceedings* containing all papers from the 3-day Conference are still available from the Network for \$29.00 (including postage). Accompanying audio tapes are also available (\$12 for a single tape, or \$11 each if two or more are purchased, plus postage).

To purchase any of these valuable resources, just contact the Network.

Membership Renewals – 1 July 2002 to 30 June 2003

With this *Newsletter* you will find one of two forms, depending on your financial status. If you are currently paid up to 30 June 2002 (as shown on your address label) you will find a **Membership Renewal Form** enclosed, for the period 1 July 2002 to 30 June 2003. Could you please confirm, complete, or amend your details as given on the form, and return it with your subscription to the Treasurer at the Network's address.

If you are already financial beyond 30 June 2002 (as shown on your address label), you will receive a **Membership Update Form** which gives your current details but does not request payment of a membership subscription. Please check your details and be sure to return the form if any amendments are required.

Members have always been incredibly supportive of the Network, and we are asking you to continue this support by renewing your membership promptly. We have recently been advised that our comprehensive funding submission (to maintain and expand the services we provide) made to the NSW Ageing and Disability Department was unsuccessful. We understand that there will be no further funding opportunities from that Department for another three years. Other avenues are continually being explored.

Did You Collect Your Information Bulletin at the Mini-Conference?

If you forgot to pick up an *Information Bulletin* at the May Mini-Conference, please let Alice know by phone (02) 9747 4694 or email alices@hotkey.net.au, or note it on your Renewal or Update Form, and a copy will be posted to you with the next *Network News*.

A Story About Three Young Men

Bryan Wishart

June 2002

Member Bryan Wishart has been a committed and generous supporter of the Network since he first made contact with us in 1999. Although not a polio survivor himself, Bryan has gone out of his way to help and encourage young polio survivors. Australia's immunisation program means that contracting polio as a child in this country is a thing of the past. This is unfortunately not true of our near neighbours. I found Bryan's account inspiring and moving, and am looking forward to regular updates on how Chi Won, Zhang-zhong and Tsung-Ta are faring.

This is about Lee, Chi Won; Liu, Zhang-zhong; and Tsai, Tsung-Ta.

Four years ago I decided that I wanted to help teenagers who had polio. At that time, the intent was to provide a few dollars every so often.

After some searching I found a seventeen year old in Korea, about one hour south of Seoul. His name is Lee, Chi Won. He contracted polio when he was six years old. Six months afterwards his family put him into a rehabilitation centre because they were too poor to look after him. This is where I found him.

A couple of months later, I found out about a junior wheelchair tennis camp in San Diego. Chi Won's profile stated that he played wheelchair tennis (and wheelchair basketball). I asked him through an interpreter if he wanted to go and he said yes.

This was an interesting trip. I met Chi Won for the first time the day before we flew out of Seoul. I had never spent any time with anyone handicapped. So, this was a very new experience for both of us. Fortunately, we got on very well and had a very good time together. And, as it turned out, Chi Won is a very talented sportsman.

I encouraged Chi Won to play on the international wheelchair tennis circuit. This has resulted in him visiting Australia four times as well as playing in Japan a number of times, England, USA and Europe. He has represented Korea in both wheelchair tennis and wheelchair basketball.

During one tennis tournament, as we were travelling by coach to the tennis courts, the president of the International Wheelchair Tennis Federation asked me how I got into this. I said "by accident". His response, sitting in his wheelchair, was "that is how most of us do".

I have had some very good times with Chi Won. From a sporting point of view, the best times were when I have seen him win tournaments.

Chi Won is now twenty-two years old. He is working, drives a little sporty car and has a girl friend.

Chi Won has stopped playing tennis for the time being and is concentrating on his job and basketball.

In June 1999, my contact found Liu, Zhang-zhong. Zhang-zhong contracted polio when he was two years old. Zhang-zhong lives in the middle of Taiwan in a home for the disabled. Zhang-zhong's family is also very poor and has difficulty looking after him.

When I met Zhang-zhong, he had an old wheelchair that did not have a proper cushion and was difficult to push around. So, I bought him a new, modern wheelchair. The happiness this brought him was worth the investment.

Last year Zhang-zhong had an operation to straighten his knees. When I saw him a couple of months later, he was so happy that he could walk, albeit wearing leg braces and using crutches. This was the first time he had been able to walk since contracting polio eighteen years previously. This was a very good alternative to just sitting in a wheelchair all day. Able-bodied people take so many things for granted.

Zhang-zhong is now starting to play wheelchair tennis more. He also plays a little wheelchair basketball.

Zhang-zhong is now twenty years old and still goes to school. I spent a couple of weeks with Zhang-zhong in May 2002. I met him at the hotel in Taipei on a Friday night and we spent the weekend together; shopping, going to movies, eating, talking. Tsung-Ta joined us for dinner on one of the nights.



Also, the three of us spent an hour in the hotel swimming pool doing a photo-shoot.

My company flew a photographer from Hong Kong to take photographs in support of an article they are writing about Chi Won, Tsung-Ta, Zhang-zhong and myself in the in-house magazine.

Left: Tsung-Ta and Zhang-zhong with Bryan in Taipei.

On the Monday, we flew to Korea. This was Zhang-zhong's first time in an aeroplane and his first time outside Taiwan. He was a little apprehensive but settled down and enjoyed the flight.

The main purpose for the trip to Korea was for Zhang-zhong to play in two wheelchair tennis tournaments: the first in Incheon (Korea Open), an hour out of Seoul, and the second (Daegu Open), a one-hour flight south of Seoul.

It is still early days with Zhang-zhong for tennis. He played in one of the lower grades and did reasonably well, showing good promise. He is keen to learn and to progress through the rankings. There are a couple of issues: he does not have his own tennis wheelchair and had to borrow one that was unsuitable and he does not have a proper coach. I am working to address both these points.

Between the two tournaments and after the second tournament we spent some time in Seoul, doing things together, including more shopping, eating and talking as well as going to an IMAX theatre.

I took Zhang-zhong to the hotel discotheque in Seoul. There he did wheelchair dancing for the first time and was excellent. This made me very happy. We also played pool.

Although I said we did some talking, this was a challenge as Zhang-zhong's English is limited and my Chinese is non-existent. So, the plan is for Zhang-zhong to spend around a month in Sydney attending English classes in July 2002.

I also did a lot of work with Zhang-zhong in helping him to walk using leg-braces and crutches. However, he had limited movement because the leg-braces go all the way up to a back-brace with hinges at each side. So, all he could really do was shuffle. But he persevered and made good progress.

All in all, we had a great time together and grew our father:son relationship enormously.

Zhang-zhong has four areas of focus:

- learn English,
- learn to play tennis better,
- persevere with walking, and
- get a job, probably in 2003 after he has finished school.

I was introduced to Tsai, Tsung-Ta in March, 2000. Tsung-Ta contracted polio when he was three years old. Tsung-Ta lives at home with his mother, father, older brother and younger sister.

Tsung-Ta represented Chinese Taipei in swimming in the 1996 Paralympics in Atlanta.

Tsung-Ta is now in his third year of a law degree. He studies very hard, going to cram school on a number of nights during the week as well as for twelve hours on Saturday and on Sunday mornings. I marvel at the effort and the commitment he is making to get his degree.

One time Tsung-Ta decided he wanted blue streaks in his black hair. So, I took him to the hairdressers and five hours later he had red streaks in his hair. He went back the following week and this time came out with blue streaks. Never again.

However, that was not as bad as Chi Won. Chi Won regularly changes his hair colour. On one trip to Australia, he turned up with bright blue hair. While he was in Sydney, he decided he wanted to change to yellow hair. I took him to the hairdresser and the treatment did not work and Chi Won came away with pink hair. Life is full of interesting moments.

Tsung-Ta always likes trying different things: visiting various museums, taking me sightseeing and eating different types of food.

In addition, when I spend time with Zhang-zhong and/or Tsung-Ta we do many things together including playing pool, going shopping, going to the movies and swimming.

Tsung-Ta is now twenty-one years old. Tsung-Ta drives a three wheel scooter to mix it with the millions of other scooters in Taipei.

Tsung-Ta is single-mindedly focussed on his law degree; one more year to go after this one. His ambition is to be a judge and I am sure that, with his determination, he will make it.

In many ways, Chi Won, Zhang-zhong and Tsung-Ta are very similar:

- powerful upper bodies,
- very mobile - wheelchair or leg braces and crutches,
- incredibly independent, and
- strong willed.

During the time I have known them, I have been able to offer them different things that they would not have been able to afford. They have also enjoyed experiences they may never have had.

I am an alternate father-figure to them and a source of tender-loving-care.

I have gained a lot of pleasure encouraging them, supporting them and helping them with their self-esteem as well as their overall development.

They are disabled. But the limitation is that they cannot use their legs properly. Besides that, they have lots of ability and talent and that is where the focus is.

This is about giving others a chance to reach their potential in life.

Some interesting moments

- After a hard day of tennis, Chi Won telling me that “all you do is push, push, push”.
- A toddler seeing Chi Won pushing himself in his wheelchair after tennis practice said to his father, pointing at the wheelchair, “car”.
- Tsung-Ta pedalling with me on a pedalo on a lake in Taipei, using his left leg with a little help from his hand.
- Zhang-zhong, upset by a drunk in a Karaoke bar, punching him from his wheelchair.
- After me encouraging Chi Won to do more walking (wearing leg braces and using crutches), Chi Won saying “all you do is push, push, push”.
- While Chi Won was driving his car in Seoul, his response to me saying “you drive fast” was “just like you”.
- Sitting in the back of a taxi with Tsung-Ta and Zhang-zhong in Taipei and the disabled driver, using hand controls, driving like a maniac in and out of traffic at high speed.
- Sitting beside a disabled taxi driver in Taipei with the driver not using hand controls but holding his leg on the pedal and moving it by hand from accelerator to brake and back.

Footnotes

Special thanks to:

- Rebecca Teng who found both Zhang-zhong and Tsung-Ta for me and acted as an interface and interpreter between Zhang-zhong and myself.
- Michael Choi who has worked with Chi Won to provide additional guidance as well as acting as an interface and occasional translator between Chi Won and myself.



Australian Foundation for Disabled - 50th Anniversary

The Australian Foundation For Disabled (Afford) began as The Poliomyelitis Society in 1952 offering care and support to polio survivors and their families. Since its formation, the Society has undergone many name changes and broadened its service delivery to assist other than polio survivors. This year marks the 50th Anniversary of the organisation and a number of activities will be held in celebration. In the last *Network News* it was reported that a reunion would be held in May. We have since been advised that this did not occur and that the reunion is now expected to be held in July. If you would like further information or wish to express an interest in attending, please ring Maureen Turner at Afford on (02) 4777 4250 or email her at polio@afford.com.au.

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.

Doctors not the only Australian opponents of Sister Kenny

Sister Kenny's departure from Australia is usually attributed solely to her conflict with doctors. However research by Phillipa Martyr, for her PhD degree at the University of Western Australia, reveals that the role of the Australasian Massage Association's (precursor of the Australian Physiotherapy Association) antagonism against Kenny has been overlooked. Kenny threatened therapists' livelihood, particularly the growth in the number and status of their workforce provided by the polio epidemics. Martyr cites numerous examples of how the Massage Association went *out of its way to discredit Kenny and to align themselves securely with the orthodox medical profession, keeping up a steady pressure on their respective medical connections which contributed to the eventual rejection of Kenny and her methods in Australia.* In Queensland, the Association attempted to prosecute Kenny because she practised *what she calls re-education ... As re-education is an essential part of physiotherapy and as Sister Kenny is untrained and unauthorised by the Board she should not be allowed to either practice or teach.* When therapists found that legally nothing could be done, they commenced investigation of Kenny's nursing background and *a steady flow of communication with other branches warning them about Kenny's activities.* One letter lamented, *It's hard indeed when our medical men support such rubbish as the Kenny method.* Worried at their inability to compete with Kenny's public profile the Association appointed two officers to publicise cases of recovery from polio after treatment by physiotherapists. Kenny visited England in 1937 and on her return to Australia said that many hospitals had offered her facilities. The Association had warned its British counterpart of Kenny's lack of credentials and used this connection to expose Kenny's claims of the British offers as false. Martyr argues that in its attack on Kenny the Association *gained state and public attention ... and thanks to its policy of association and alliance with the medical profession it had gained the advantage.* Martyr notes that ironically much of Kenny's method was integrated into physiotherapy. *Kenny herself had not been legitimised but her methods of treatment had.* Interestingly the website of the Kenny Memorial fund (which in conjunction with the School of Nursing at the University of Southern Queensland is hoping to raise \$1.5 million to establish a Sister Elizabeth Kenny Professorship in Rural and Remote Nursing) describes her method as *hydrotherapy in warm salt baths, extended manipulation of affected arms and legs, together with daily massages ... much like contemporary physiotherapy.*

PPS ends Arthur Clarke's travels

Reuters (6/11/01) reported that *Wheelchair-bound science fiction writer Arthur C Clarke says he plans to spend the rest of his days in his adopted home Sri Lanka because he no longer has the energy for overseas travel. Clarke, 83, widely acclaimed as a prophet of the space age, said the crippling post-polio syndrome has forced him to decline an invitation for a gala dinner in his honour at the Playboy mansion in Los Angeles. "I can no longer face overseas travel", said Clarke in a videotaped message to the gala ... "I am completely wheelchair'd owing to post-polio syndrome and am very limited in time and energy".* The report described Clarke as *one of the most celebrated science fiction writers of all time. He*

has seen many of his predictions come true, including a then-controversial 1945 theory of a world linked by geostationary satellites.

Iron lung baby discovers her past

A story in *The West Australian* (28/12/01) about 53 year old Jan Findlay, *Australia's first iron lung baby*, reflects how attitudes regarding the capabilities of parents with disabilities and the wisdom of doctors have changed in the last half century. The story tells how Jan was reunited with her birth father, Jack Clark, last Christmas. Jan's mother Betty Clark contracted polio in 1948. She was briefly removed from her iron lung to give birth to Jan. Betty returned home after four months and on doctors' advice put Jan up for adoption. Jack said *I didn't want a bar of it at the time because I didn't want to lose my daughter. The doctors said Betty would never be properly able to look after the baby so we didn't really have a choice at the time.* After the adoption Betty returned to hospital for a further year of rehabilitation and Jack looked after their son. Jan, who learnt that she was adopted 14 years ago, only recently managed to trace her father. Betty died in 1985. Jan said *she felt no resentment about being adopted ... "That was just the way they did it in those days", she said.*

The last iron lungs

On 17 February Associated Press USA ran a story, *Woman Spends 51 Years in Iron Lung*. It tells of Diane Odell of Tennessee who contracted bulbo-spinal polio aged 3 and still uses a 7-foot long, 750-pound iron lung. Iron lungs were first used in 1928 but by the late 1950s were largely replaced by positive-pressure airway ventilators. Production of iron lungs ceased in the USA about a decade ago. The manager of a Pittsburgh company that manufactures home ventilators is quoted as saying that *only about 75 to 100 are still in use today ... In some cases they are not used all the time. About 200 iron lungs exist that can be recirculated among people who need them.* Diane can speak when breathing out. She uses 'sip and blow' switches that allow her to operate a television. Using a voice-activated computer she wrote a children's book, *Less Light*, which is the story of a tiny star named Blinky who dreams of becoming a wishing star. Diane is currently writing her autobiography because she wants *to show children, especially those with physical disabilities, that they should never give up. 'Its amazing what you can accomplish if you see someone do the same thing' she said.* Diane obtained her high school diploma working from home and has an honorary college degree. Her parents and married sisters care for her. Recently a fund-raising gala event attended by 1,100 people including Al Gore, the former Vice-President, raised \$US110,000 to establish a foundation that will care for Diane when her parents are unable to do so. She attended the event in her iron lung that was draped with an American flag. She wore a sequined dress and tiara. *Diane said she feels blessed with good friends and a good family, and she is thankful. 'I've had a good life'.*

A similar decline in the use of iron lungs in the UK is described in *The History of the British Iron Lung* (www.geocities.com/ironlungmuseum/ironlung.htm). In 1968 St Thomas' Hospital in London began selling off its iron lungs. The Melbourne museum has an iron lung from the old Fairfield Infectious Diseases Hospital. It is decorated in red and black as its former inhabitant was an Essendon supporter and can be seen on the Web at www.museum.vic.gov.au/hottopics/article.asp?ID=324.

In Sydney, Network member Gabby Hannemann has been sleeping in the same iron lung since 1967, when it came home with her from Prince Henry Hospital. She was 10 years old at the time. Because of the age of the lung, maintenance is becoming something of a problem. As far as Gabby knows she is the only person in NSW still using an iron lung, and she feels this probably adds to the maintenance problems as no-one is learning about them now - the iron lung is considered obsolete. Gabby would be interested in hearing from any other polio survivors still using an iron lung, particularly with a view to sharing information on how they are coping with problems arising from the age of their units.

Polio survivors used in overuse injury research for military

An article on polio published in *The Dallas Morning News* (12/1/02) wrote about the late effects of polio: *Doctors attribute the symptoms to overused muscles, a cruel twist of fate because survivors were encouraged to work the muscles hard during rehabilitation. 'The medical community pushed them a lot', said Dr Mary Ann Keenan, a polio specialist at Philadelphia's Albert Einstein Medical Center. 'They had much weaker muscles than we perceived. We also underestimated how hard the everyday activities of life are, especially when they don't have that muscle strength.'* Dr Keenan argues that more research could not only pay off for polio survivors, but also have long-term benefits in the study of neurological and rehabilitative disorders. She recently received a \$1 million grant from the Army to investigate overuse injuries. Keenan uses post-polio patients in this research. Because they are susceptible to an accelerated pattern of overuse symptoms the post-polio population provides an excellent model for the study of overuse disorders in the general population Keenan said in an article she and her colleagues published in the *Archives of Physical Medicine and Rehabilitation* (volume 81, June 2000). She explains that overuse injuries occur directly when weakened muscles must work harder to maintain a certain force or indirectly when alternate muscles are recruited to compensate for weakness. Sometimes people are not aware that they are overusing muscles to compensate for undetected subclinical weakness. She has found that among polio survivors, those with leg weakness are more prone to shoulder overuse injuries, as are younger and middle-aged survivors probably because they lead more active lives than older retired survivors do.

Left behind by the discovery of polio vaccine

Articles on the history of polio sometimes show photographs of patients in polio wards celebrating the discovery of the Salk vaccine. Yet the reality was that this discovery resulted in the termination of most research into the treatment of polio and the loss of doctors' interest in polio patients. As Wilfred Sheed, a British born American journalist who contracted polio aged 15, wrote in his autobiography: *They never did learn very much about polio except how to prevent it. Sheed confesses that he was surprised at the force of my irritation the day I first read about Dr Jonas Salk and his famous vaccine. I could have sworn I knew better than that by this time — knew for instance, that I wasn't going to get my legs back now, whatever anyone discovered the switchboard of my spine had been dismantled years ago — and knew from observation that a lot of two-legged people are absolutely miserable ... Yet here I was flinging the overseas edition of Time magazine against the wall of my Oxford sitting room so hard that the staples fell out. What had taken the man so long? ... I was back where I began, pounding the sky with my fists and hoping for a cure. Well this really was the end, baby. There'd be no more research now for sure, and no more gleams under the door, or hopes so small and crazy that I hid them even from myself. It was a small loss and a huge one at the same time, but I guess what gripped me most wasn't my own totally hypothetical loss as the spectacle of all those people smiling and cheering as the last boat pulled out ... I guess the message for the poor wretches on the dock was ... they didn't even seem to be looking in our direction any more. We were last year's cover story now.*

I must admit to having a similar reaction at some post-polio conferences that have had as their keynote address a talk on the success of the polio eradication program. Of course I'm delighted that people, particularly my children, will no longer be vulnerable to polio but such addresses, which are invariably the best news delivered at the conference, have nothing to offer polio survivors for whom such conferences are held.

(*In Love with Daylight*, Wilfred Sheed's autobiography, was published by Akadine Press in 1999. Much of it concerns his later fight with cancer.)

Polio facades

The effort polio survivors put into denying or minimising their disabilities and the way PPS can demolish such facades is vividly described in Sheed's biography. He writes, *I had taken the art of concealment to such dizzy heights that I was genuinely surprised now by offers of help: where had I gone wrong this time? If I stumbled, I had learned to stare balefully at a nonexistent pothole until the others could almost see it too, and if I outright fell, I was up so fast it seemed like an optical illusion. Or so I hoped. The truth is I was probably always a lot more handicapped than I let on, either to myself or others. My knacks were all geared to the same end, a massive cover-up, a downright Watergate of the nerves and muscles, in order to pass inspection. As Bernard Shaw said of duchesses, if people treat you like one, you are one; and I worked on my walking as assiduously as Eliza Doolittle worked on her talking: not just to do it better, which is hard, but to fool people, which is surprisingly easy. And I would receive my reward for all this spit and polish, when someone I knew slightly would exclaim on, let's say, our third meeting, 'What's the matter — did you hurt your leg?' It was like smuggling the Hope diamond past smiling Customs officials. But I was like a regiment trained to parade better than fight, and when the so-called post-polio syndrome hit me in my mid-fifties, it weakened the whole physical apparatus just enough to call my bluff on all fronts at once — and no one could have been more surprised than I to realize quite how much I had been faking it all these years.*



The History of Prince Henry Hospital on CD

The history of The Prince Henry Hospital has been recorded on a set of CD-ROMs by the *Little Bay Coast Centre for Seniors*.

In 1999 the Centre accepted a Federation Grant to produce CDs on the history of The Prince Henry Hospital, which was originally known as The Coast Hospital. The Hospital celebrated its 120th anniversary in September 2001.

A three-CD set is now available which features a tour of the hospital led by Dr Ralph Hockin, its longest-serving medical superintendent. You can contact the Centre on (02) 9382 5371 to purchase a set of the CDs for \$15 plus postage.

The three CDs are the first of several covering the history of The Prince Henry Hospital. The Centre, which now has a well-equipped multimedia centre, will continue to record changes being made to the Little Bay site as it moves into a new era.

Raffle Winners

The Raffle to help fund Conferences and Seminars to bring up-to-date post-polio information to members was drawn at the Mini-Conference on 18 May. The following members and friends were the lucky winners:

Myer Gift Vouchers (\$1,750) were won by H Drady (Lyndhurst)

A financial plan / needs analysis (\$1,440) was won by Sister McFadden (Kensington)

Family variety hamper (\$500) was won by C & B Maurice (Bateau Bay)

Oil / electric heater (\$200) was won by Lynette Bray (Lapstone)

Leoma Collection quilted decorator bedspread (\$180) was won by Doug Sutherland (Burwood)

Hand-made, home-spun wool knitted blanket (\$150) was won by John Cerniauskas (Wollongong)

Hand-stitched cross-stitch wall hanging (\$100) was won by Ralph Buck (Seven Hills)

The Management Committee expresses its deep gratitude to all members and their families and friends who bought and sold tickets in support of the Raffle.

Support Group News

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In mid February I journeyed north from Albury to try to catch up with old friends and colleagues as well as visit some convenors. My first stop was in **Griffith** where I met and was made welcome by **Dawn Beaumont-Stevens**. Dawn is our only voice in the Riverina and we are extremely grateful to Dawn for conducting a telephone support service in this vast area of the state.

Following a stopover at my hometown of Dubbo I continued north but was held up by a mechanical breakdown at Quirindi and was late into **Kootingal** where one of our **Northern Inland** members, **Laurie Seymour**, and his wife, **Beryl**, live. I was very relieved to finally reach them and joined them for tea which was most welcome and very much appreciated. Laurie edits a newsletter *The Link* which he distributes to many members in the north and other parts of the state. I know that he would love to receive contributions from members who receive it.

At **Ballina** I was pleased to catch up with **Northern Rivers** convenor, **Rosalie Kennedy**, and her assistant, **Fae Mortimer**. We enjoyed a very tasty morning tea which Fae obtained on the way home from a late night outing. Rosalie and Fae conduct an active support group which meets every two months at a number of venues.

Whilst in this part of the state I was disappointed not to catch up with convenors **Susan Stewart** from **Grafton** and **Ken Dodd** of **Coffs Harbour** who both had commitments in Sydney at the time of my visit, but there will always be a next time.

I then proceeded south to **Muswellbrook** where I met **Bruce Bulls** who is convenor of the **Upper Hunter** Support Group. Bruce would very much like to hear from any members who live in the vicinity of Muswellbrook, Scone, Denman and Murrurundi. You can contact him on (02) 6545 1993.

On my return through **Dubbo** I caught up again with convenor **Gregg Kirkwood** who has received enquires from a number of polio survivors. As I completed the last leg of my trip I called in on my old friend **Jean Robinson** who was our convenor in **Young**. Unfortunately Jean passed away a few weeks later and we extend our condolences to her family. Jean had a wonderful spark and spirit and should be an example to all of us.

May I express my sincere thanks to all convenors who made themselves available to see me during my tour and for extending their very welcome hospitality.

The **Eastern Suburbs** Support Group under the guidance of **Eric Sobel** has attracted several new members. The meeting held on 15 June at the Labor Club in Randwick saw eight enthusiastic members in attendance. The group is now getting together on the third Saturday of every second month and for the next meeting on 17 August have decided to change the format to include lunching together prior to the normal information exchange. Any member living in the Eastern Suburbs is welcome to join the Group - ring Eric on (02) 9389 7967 for more details.

In an endeavour to broaden the base of our support network, at the last Management Committee meeting it was agreed that we should create another classification – that of **Support Network Contact Person**. This person would not have the responsibility of convening a Support Group in a particular area but would simply be a contact person for the Network in their local community, whether it be country or city. Further details will be provided in the next Newsletter, however, if you are interested in obtaining more information please ring or email me.

Post-Polio Post



I was delighted to receive this letter from Judith Plummer, daughter of member Marjorie Corby, Taree. On checking dates of birth in the membership files, I found that our records show Marjorie is our oldest member, having been born in 1910. It is great to hear that she is still going strong and with such wonderful family support. I will look forward to hearing from Judith again.

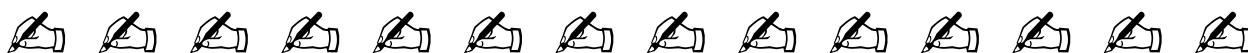
Sitting down to fill out a cheque for subscription renewal, I wondered if you would like to know about my mum – a PPS survivor.

Mum contracted polio in 1921 when it was known as Infantile Paralysis and affected the right side of her body. She grew up, married and had five children. When war was declared, my father joined the army and was posted overseas in April 1940 and did not return, leaving mum to raise us on her own on a “deserted wife” pension.

Mum strived to keep us all together and we never realised how hard her life must have been, looking after five children. I remember washing day each week, she would fill the copper and light it at 7 am in the morning and still be washing when I came home from school at 3:30 in the afternoon. Her greatest delight was when my oldest brother bought her a second-hand Hoover washing machine with a hand wringer when he became an apprentice butcher. The muscle weakness became more obvious as mum used to trip very easily and became tired and fell asleep over the ironing board – increasing to where she is in 2002.

Mum is now 91 years old and 95% wheelchair dependent because of PPS. From her five children, she has eighteen grandchildren and to date, thirty-seven great grandchildren. I am the youngest, a daughter, and I live with mum in her retirement villa as her carer.

All of us love her dearly, her tireless devotion to our earlier years more than likely resulted in her symptoms today and now it’s our pleasure to look after her.



Coming Events – Dates To Remember

Saturday 3 August	St Paul’s Anglican Church Hall Princes Highway <i>Kogarah</i>	<i>Murder at the Sydney Opera House</i> a musical murder mystery in one act in the Agatha Christie short story tradition <i>written and performed by Barbara Thompson</i>
Saturday 31 August	Northcott Society <i>North Parramatta</i>	<i>Living with Polio – A Family Affair</i> A Seminar for you AND the important people in your lives <i>presented by Adam McLean</i> Counselling Co-ordinator, Carers NSW
Friday 25 October	Regency Function Centre Burwood RSL	<i>Social Event - Reunion Luncheon of Polio Survivors and Hospital Nurses</i> <i>Everyone is welcome</i>
Saturday 30 November AGM and Seminar	Independent Living Centre Victoria Road <i>Ryde</i>	<i>Falls, fear of falling and activity in older people with polio: what can be done to help?</i> <i>presented by Dr Keith Hill</i> Senior Research Fellow, National Ageing Research Institute (NARI), and Co-Director, Falls and Balance Clinic, Melbourne Extended Care and Rehabilitation Service