POST - POLIO NETWORK (NSW) INC.

NEWSLETTER

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President's Corner

Gillian Thomas

Greetings to all. There is a range of information in this issue to please all tastes, with our feature article appearing on pages 3 - 8. On page 2 you will find the **Program** for the **Mini-Conference** to be held in **Canberra** on **Saturday 29 August**. This is your last chance to register to attend a most informative day. **Support Group Conveners** from across New South Wales are also coming to Canberra for a **Workshop** on **Sunday 30 August**. Bernie O'Grady, Support Group Co-ordinator, has an update on this inaugural Workshop in his report on page 13. If you are thinking about convening a Support Group, you should be there - just give Bernie a ring.

Thank you to everyone who has renewed membership for 1998/99. So far, 78% of the members are financial. If the top line of your address label still reads 1998 instead of 1999, we have not yet received your renewal. Please forward it promptly, using the form sent out with the last Newsletter. While on the subject of renewals, the Management Committee has asked me to pass on our sincere thanks to the large number of members who have generously made donations to help our work for polio survivors. Since the Network receives no funding, we rely on membership subscriptions and donations (not to mention many volunteer hours) to keep the Network going, and your generosity is very much appreciated.

Thank you also to all those members who have again come to our assistance by offering to promote the Network and raise community awareness of the late effects of polio by participating in the annual **Post-Polio Awareness Week**, being held this year from **1 - 7 November**. If you would like to help but haven't yet sent back the form, can you please do so before the end of August. For more information about the Week, or about how you can become involved, please ring Janet on (02) 9787 1042, or Alice on (02) 9747 4694.

Next year we will be celebrating our **tenth anniversary**. This is quite a milestone for a self-help group such as ours. If you have any ideas about how we can celebrate this important event, please get in touch with me. We would like to involve as many members in the celebrations as possible. We expect that the **raffle** which has been deferred from this year will be drawn as part of the celebrations. Thank you to all those members who have agreed to assist in our fund-raising by selling raffle tickets. Proceeds of the raffle will go towards holding Seminars in country areas.

We have at last moved into our **office** within the *Royal South Sydney Community Health Complex*, Joynton Avenue, Zetland. There is still a lot of work to do before the office is up and running, but we are hoping it becomes operational in September/October. Office Co-ordinator Ruth Wyatt [(02) 9416 4287] has asked me to pass on her gratitude for the offers of help which have come in so far to man the office. We can always use more help to lessen the load on the Management Committee. Remember that working as a volunteer for the Network may also help you to qualify to receive the *Mobility Allowance*. Ruth is hoping to hear from you soon.

Finally, I'm looking forward to meeting many of you for the first time in Canberra at the end of the month. Remember that the next Sydney **Seminar** - and the **AGM** - is on **Saturday 31 October**.

Managing the Late Effects of Polio

Saturday 29 August 1998

ACROD House, 33 Thesiger Court, Deakin ACT

ACROD House is a large, light, airy venue which is heated to keep the winter chills at bay. There are accessible facilities on site and ample parking is a short level walk (or wheel) away. The Conference Program focuses on the practical aspects of managing the late effects of polio. The day's proceedings will be tape-recorded. The **registration cost** is **$20**, which **includes morning and afternoon tea and a hot lunch**. If you are accompanied by someone to assist you, that person may attend at no charge. Dinner in the evening will be at the wheelchair-accessible Yamba Club, Irving Street, Phillip. The ACT Support Group has negotiated a discounted price of $12 per head for a bistro meal in the Club's lower level room. **If you have not yet registered but wish to attend, please ring Gillian on (02) 9663 2402 as soon as you receive this Newsletter.**

CONFERENCE PROGRAM

9:30 *Registration and Tea/Coffee*

10:00 **Welcome and Opening Remarks**
Gillian Thomas [*President, Post-Polio Network (NSW) Inc*]
Brian Wilson [*Convener, ACT Support Group, Post-Polio Network (NSW) Inc*]

10:15 **Keynote Address**
Dr Pesi Katrak [*Rehabilitation Specialist, Prince Henry Hospital*]

11:00 *Morning Tea*

11:30 **Questions**

12:00 *Lunch*

1:00 **Wheelchairs and Beyond**
Chris Sparks [*Dynamic Living Designs Pty Ltd*]

1:30 **Be Kind to Your Feet**
Richard Lee *[The Walking Clinic]*

2:00 **Questions**

2:30 *Afternoon Tea*

3:00 **Swallowing, Breathing and Voice**
Trish O'Sullivan [*Speech Pathology Department, Concord Hospital*]

3:30 **Ask The Panel**

including	Gillian Thomas	*Post-Polio Network (Chair)*
	Dr Pesi Katrak	*Rehabilitation, Prince Henry Hospital*
	Ron Bennett	*Surgical Orthopaedic Services*
	Jac Cousin	*Canberra Physiotherapy Centre*
	Ian Neering	*Consultant*
	Trish O'Sullivan	*Speech Pathology, Concord Hospital*

4:30 **Closing Remarks**
Gillian Thomas [*President, Post-Polio Network (NSW) Inc*]

Differentiating Post-Polio Syndrome from Aging

Steven T Dinsmore

Steven T Dinsmore, DO, is Assistant Professor of Clinical Medicine at the Center for Aging, University of Medicine and Dentistry of New Jersey, School of Osteopathic Medicine, Stratford, New Jersey.

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Post-polio syndrome demonstrates the difficulty of separating disease from normal aging. When individuals first presented with symptoms of post-polio syndrome, many were told they were just getting older. Some are still given this explanation. To a certain extent this is true, but experience and thoughtful observation reveal a process above and beyond normal aging. There is a slow multisystem decline in aging that interacts with the injury sustained during acute poliomyelitis. In the life of post-polio survivors, a degree of disability emerges that places them on a different trajectory from the slow accumulation of disability experienced in normal aging.

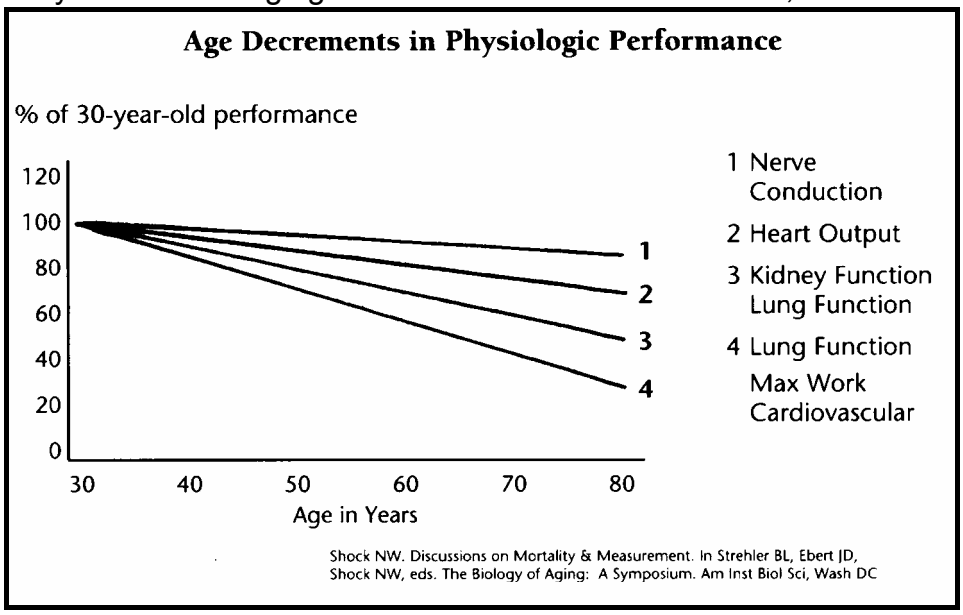
Etiology of Aging

The overall cause of aging itself is not known. There are probably several mechanisms operating simultaneously that produce age-related decline in organ and tissue function. In some cells, reproduction is limited to a certain number of generations; distant organ failure may change the systemic milieu in a way that negatively alters cell function. Subtle conformational changes in critical proteins of cell metabolism may damage some cell types. In neurons, the accumulation of byproducts of cellular metabolism during the lifetime of the cell may be injurious.

Changes of Normal Aging

In normal aging there is a slow multisystem decline. The onset of decline and rate of change vary from organ to organ.

The heart is fairly resistant to aging. The size of the heart is similar, however the thickness



of the heart wall is slightly increased. Early diastolic filling is reduced. There is age-related decrease in maximum heart rate but a compensatory increase in volume per beat.

Maximum oxygen consumption is reduced with age but it is uncertain if this is due to decreased cardiac output or decreased peripheral uptake of oxygen.

The forced vital capacity of *the lungs* decreases after age 27 by approximately 25 ml/year [1]. The surface area of the air sacs in the lungs decreases by 4% per decade after age 30 [2] [3] [4]. These changes resemble those in emphysema.

Renal (kidney) blood flow is decreased from 1200 ml/min in youth to 600 ml/min at age 80.

How well the kidney removes waste products from the blood is stable until the middle of the fourth decade, then declines.

Immune system changes also occur with aging [5]:
- the involution of thymus gland;
- antibody response to vaccination decreases;
- autoantibodies (antibodies to self structures) increases;
- T-cell function diminishes;
- T suppressor cell function increases.

Infectious diseases such as pneumonia and influenza rise exponentially after the age of 25 along with an increased incidence of cancer and autoimmune disease [6] [7].

Changes in *the brain* with normal aging include:
- A decrease in weight;
- A decrease in cortex nerve cell size;
- A decrease in the speed of central processing;
- A significant decline in long-term memory (delayed recall) by age 50 [8];
- A loss of substantia nigra neurons, (400k @ birth, 200k @ age 80). These are the cells of paramount importance in Parkinson's disease. When the count drops to between 200k and 100k, individuals become symptomatic with Parkinson's disease;
- Aging of an important population of brain motor neurons (basal ganglia).

Large samples of the population studied in the course of standardization of the Wechsler Adult Intelligence Scale (1955) indicated that there is a steady decline in cognitive function, starting at 30 years of age and progressing into the senium. All forms of cognitive function demonstrated decline, although certain elements of the verbal scale (vocabulary, fund of information, and comprehension) withstood the effect of aging better than those of the performance scale (block design, reversal of digits, picture arrangement, object assembly, and the digit symbol task) [9].

The aging *neuromuscular system* is of most interest in the post-polio syndrome. Tomlinson and Irving have provided evidence that the motor neuron pool is stable until approximately age 60. Thereafter the motor neuron population diminishes. In some cases motor neuron numbers may decrease to 50% of the middle life count [10]. There is also reduced terminal sprouting [11] [12]. In individuals over 65 it is not uncommon to see fiber type grouping (unpublished observations) which supports the observation of motor neuron dropout.

In addition to the alterations in the motor neuron there is change in muscle. It is observed that there is loss of muscle mass with aging [13]. This loss will cause increased use of the remaining muscle for activities of daily living and, subsequently, may further stress those motor units already at the threshold of maintaining performance.

The Motor Unit in Post-Polio Syndrome

In people who had acute paralytic poliomyelitis there is electrophysiologic evidence that the motor unit is unstable. Fibrillation potentials, positive sharp waves, and fasciculations are

observed in muscles of post-polio individuals who have no new complaints [14]. These findings imply that the motor neuron is not performing normally. This instability can be demonstrated throughout the life of the polio survivor and worsens as the individual ages [15]. These findings represent a continuous remodeling of the motor unit occurring at the level of the terminal nerve. As some terminal nerve/muscle connections are lost, the orphaned muscle may be reconnected to a terminal nerve from another motor neuron. A time comes when the disconnection rate overtakes the reconnection rate. Subsequently muscle fibers are lost and new weakness begins. This critical threshold is more related to the time since the acute poliomyelitis rather than absolute chronologic age. New weakness that is noted at age 45 is a significant divergence from normal aging on two counts. First as noted, age-related motor neuron and terminal nerve loss are deferred until age 60. Second, in normal aging the weakness that accrues is subclinical.

it is the change in the motor unit which is at the heart of the post-polio syndrome and, in light of the observed electrophysiologic alterations in the motor unit, it is evident that the post-polio motor unit is not behaving as a normal aging motor unit. There are three possible causes for this altered performance.

1. The motor unit is expanded

Many motor neurons are carrying a greatly increased load of muscle fibers to compensate for those motor neurons that were lost during the acute poliomyelitis. It is uncertain if the cellular metabolic machinery can carry this increased load for a lifetime. Those motor neurons that escaped from acute poliomyelitis uninjured may be injured later by this chronic increased load.

2. Not all surviving motor neurons escaped uninjured

Many neurons showed evidence of injury but subsequently recovered [16]. These motor neurons may have an unpredictable lifetime performance and especially be unable to support an expanded motor unit.

3. Motor units are stressed by an increased demand for firing

It has been demonstrated that the select muscle groups are greatly overused [17]. The motor neurons controlling the motor units within these muscle groups are also overfiring. This may have a long-term damaging effect.

Aging and Post-Polio Syndrome

I do not wish to imply that aging is not a factor in post-polio problems. Certainly the length of time a motor neuron carries an increased burden is critical. But it is the aging process itself that underlies the tendency of cell function to be less effective over time. There is something inherent in the youth of the neuron, or something lost with cell aging, that allows a young motor neuron, injured or uninjured, to be capable of handling an expanded muscle fiber population.

Immunologic findings in post-polio syndrome may or may not be related to aging. These findings may include: an increased CD4/CD8 (helper/suppressor) ratio [18], an immune activation where unexpected, a MHC class I expression in muscle, and an infiltration of muscle with lymphocytes and macrophages. Spinal cords of survivors who had poliomyelitis examined years after the original injury revealed mild perivascular and intraparenchymal inflammation. Some have also revealed oligoclonal bands in the cerebral-spinal fluid [16] [19]. These observations are consistent with an upregulation of

immunologic function, possibly an autoimmune action. If an autoimmune process is present, this is in keeping with the observation of increased autoimmunity with aging.

There is a slow multisystem decline in aging which becomes a factor but is not the cause of post-polio syndrome. For example, increased cardiopulmonary demands that have always been present due to a sub-optimal gait or body mechanics become more critical as age encroaches on cardiac and pulmonary reserve. Decreased pulmonary reserve due to scoliosis crosses the threshold and becomes functionally limiting due to loss of lung elasticity and diminished ventilatory capacity of aging. These changes of aging would have been silent in a similar aged individual who never had paralytic poliomyelitis.

In summary the physiology of normal aging is a slow multisystem decline. Post-polio syndrome is a more rapid oligosystem decline (neuromuscular). The divergence in performance of the post-polio syndrome individual from the course of normal aging represents a distinct pathophysiology. However, the pathology of aging likely plays a role in the emergence of the post-polio syndrome.

Post-Polio Syndrome and Aging: Clinical Features

In normal aging there is loss of muscle mass [13]; some may be due to disuse. The loss of strength does not usually become functionally meaningful in the healthy elderly. Modest osteoarthritis produces only minor disability. The cause of greatest decline in performance is due to change in central motor control. The average individual also complains of some loss of productivity and decreased stamina. In disease-free aging, there is a gradual, almost imperceptible decline in function due to the combined effects of declining cardiopulmonary capacity, muscle strength, central motor control, and accumulating osteoarthritis.

The post-polio person also experiences these changes, which may be noted at a much earlier age (45 vs 60). Change is also much more dramatic then seen in normal aging. Loss of muscle strength is focal; if multifocal, it may lead to marked disability. The fatigue and loss of stamina is profound and disabling as opposed to a nuisance in normal aging. The osteoarthritis seen in the hips and knees of an individual with abnormal gait may also be profound.

In practice, the post-polio person stands out from the average geriatric center individual on several counts (Table 1). Polio survivors are usually 10 years younger. Their symptoms are more constrained to new weakness and fatigue indicating an oligosystem (1 or 2 system) failure vs multisystem failure. A typical geriatric patient has one or more medical problems. For example, a prior pneumonia and cardiac disease is a common combination. A modest fatigue is sometimes present, but is accounted for by a clear medical problem. Profound fatigue is uncommon. A complaint of specific focal new weakness is even more uncommon. Thus the post-polio survivor with their defining features usually stands out on this basis alone.

Table 1

	Aging	Post-Polio Syndrome
1.	No polio history	Old paralytic poliomyelitis
2.	No residual biomechanical disadvantage	Residual biomechanical deficit
3.	Mild diffuse loss of muscle mass, little functional impact	Focal moderate to severe loss of muscle strength and muscle mass with significant functional impact
4.	Mild to moderate nuisance fatigue	Moderate to severe disabling fatigue
5.	Cardiovascular, pulmonary, or cerebrovascular diseases most prominent	Neuromuscular complaint most common
6.	Slow imperceptible decline in multiple systems	Slow to moderate decline in neuromuscular performance
7.	Symmetric osteoarthritis	Asymmetric osteoarthritis

Post-Polio Syndrome vs Aging: Interventions

Interventions to promote neuromuscular and cardiovascular fitness are different in the post-polio and general population (Table 2). Increasing muscle strength may be accomplished by conventional techniques of muscle training constrained only by the cardiac and orthopedic status of the individual. An otherwise healthy elderly individual may enter graduated weight training. As their training progresses they are able to increase their limit to produce a modest degree of soreness and fatigue. This approach would be deleterious to a post-polio survivor. In short, the training principles for the geriatric population are parallel to those of the younger adult population with allowances made for baseline cardiovascular and joint condition. In the post-polio individual there must be no residual pain and minimal fatigue after training. Some post-polio people are unable to pursue cardiovascular or strength training due to extensive motor neuron and attendant muscle loss.

Table 2

Goal	Aging	Post-Polio Syndrome
Maintain muscle strength	Strength training	Modified non-fatiguing, paced strength training of affected extremities
Cardiovascular fitness	Aerobic exercise	Modified non-fatiguing aerobic exercise
Increased stamina	Exercise and activity	Carefully meter physical activity
Optimum physical performance	Physical therapy to involved areas - orthotic and assist devices	Physical therapy in the form of muscle training only in special situations - orthotic and assist devices as needed

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Are You Being Treated for High Blood Pressure?

The Polio Medical Alert Card advises that certain drugs may worsen the symptoms of post-polio syndrome (PPS), and that such drugs (which include beta blockers used in the management of high blood pressure - hypertension) should be avoided or used with caution. Some members who currently take beta blockers have sought more information. Dr Henry Holland (an American doctor who is also a polio survivor) recently posted his thoughts on this topic on the Internet, and with his permission I repeat them here for the benefit of members. As always, don't forget to advise your doctor that you have had polio, and discuss any concerns you may have about drugs being prescribed. Do not cease taking any prescribed medicine without consulting with your doctor.

Anti-hypertensives are prescribed to treat hypertension, usually defined as a sustained blood pressure higher than 140/90. A sustained diastolic (the lower number) blood pressure of over 100 usually warrants the usage of anti-hypertensives. If diet or other life style changes do not lower the blood pressure, then anti-hypertensive medication is usually indicated.

There are many types of anti-hypertensives. These medications can cause side effects for anyone, not just PPSers. Many times finding the right drug or combination of drugs is a trial and error process. I do not know of any anti-hypertensives that are absolutely contraindicated for PPSers. Beta blockers probably cause more side effects for PPSers than the other choices. Without these medications, there is a greater risk of developing hypertensive cardiovascular disease which can increase the risk for myocardial infarction, congestive heart failure, stroke, dependent edema, phlebitis, pulmonary hypertension, and other vascular related disorders. I am currently taking a small dose of a diuretic (hydrochlorothiazide), a moderate dose of a calcium channel blocker, and a moderate dose of an alpha blocker. A beta blocker alone worked very well for me a few years ago. However, I developed bronchospasm which affected my respiratory function. My point is that PPSers have to be considered individually when it comes to managing hypertension. The goal is to maintain blood pressure in a normal range. So, if you are taking a beta blocker, have no detectible side effects, and your blood pressure is normal, then it would seem wise to continue this drug until there is some reason to change. Many people, not just PPSers, have difficulty finding a suitable drug or combination of drugs to manage hypertension.

ROLLING ALONG

Grace R. Young, MA, OTR

 Grace, a polio survivor, is a semi-retired Occupational Therapist. Each month on her Internet site she publishes a new tip for polio survivors about energy conservation.

Many of us who had polio were pushed to exercise vigorously and discard canes, braces, and wheelchairs as quickly as possible. The primary goal was to become "normal" and this meant casting off equipment and doing everything other people did. To us and our families, continuing to use equipment meant that we had not been "cured". Therefore, it is not surprising that we feel a sense of failure if we have to start using wheelchairs or scooters or return to the equipment we left behind many years ago.

Two social workers who are also polio survivors have written about the positive benefits from seeing oneself as disabled (see reference). These include:

1. allowing yourself to be pleased with whatever you have accomplished;
2. allowing yourself to join support groups which provide an emotional environment for the expression of the painful feelings which accompany physical loss;
3. letting yourself discard the false pride which has prevented you from using equipment which would help you meet the demands of life.

Canes or crutches may suit your needs when you're at home or need to ambulate very short distances. However, using a wheelchair or electric scooter for longer distances or in challenging situations may actually prolong your ability to walk by preventing overuse of your legs. And there are other advantages to using wheelchairs or electric scooters instead of canes and crutches.

Long-term use of crutches or canes can cause secondary complications such as compression of nerves in the neck area (thoracic outlet syndrome) or wrist (carpal tunnel syndrome), which can cause pain and numbness in the arm and hand and eventually affect function in the upper extremity.

Continuous use of crutches or canes can cause gradual weakening of shoulder and arm muscles, even if these areas did not appear to be affected during the initial attack of polio. Remember that some muscles may have suffered subclinical damage - that is, some motor units were lost during the acute attack but not enough to be obvious during normal usage. The use of canes or crutches over a long period of time can overwork the remaining motor units.

And last - but not least - ambulating uses a tremendous amount of energy when you have considerable weakness in your leg muscles.

Manual Wheelchair VS. Electric Wheelchair VS. Motorised Cart (Scooter)

The main advantage to a manual wheelchair is its portability. It folds easily and comes as light as 27 lbs, which is too heavy for most polio survivors but could be lifted easily by a non-disabled companion. It fits into most automobile trunks.

The main disadvantage is that long-term pushing may lead to the same problems as using canes and crutches - pain and increasing weakness of the shoulder muscles. Nothing is gained if you conserve your legs but overwork your arms.

There are many factors to consider when deciding between a scooter and an electric wheelchair. Either one is an expensive purchase, so you need to anticipate what your physical condition will be like in the future.

Using an electric cart requires enough leg and trunk strength to transfer on and off the seat. It entails adequate trunk balance and upper extremity strength and endurance as you need to reach forward and maintain a grip on the tiller, which can be fatiguing to the hands and shoulders. If you are experiencing increasing weakness in your shoulders, hands, or upper body muscles, consider whether an electric wheelchair will fit your future needs better than an electric scooter.

Electric mobility aids do present a transportation problem. There are many types of lifts available for vehicles, and you need to seek input from a physical or occupational therapist who is experienced with this type of equipment. The main thing to look for in a lift is: can you get the wheelchair or scooter in and out of the vehicle independently and without physical stress.

Reference:

C Carsey and J Tepley 1986, *Facing Disability*, Rehabilitation Gazette, 27:6-7.

The Post-Polio Institute "Hypoglycemia" Diet

Dr Susan J Creange

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Dr Richard L Bruno

Director, The Post-Polio Institute, Englewood Hospital and Medical Center,
and Chair, International Post-Polio Task Force

The most recent research at The Post-Polio Institute has shown that polio survivors with fatigue have slowed brain waves, reduced levels of brain activating hormones and a significantly decreased ability to think of words they want to say, pay attention and concentrate. Dr Susan Creange has discovered that polio survivors with blood sugar levels in the low normal range have as much difficulty paying attention and concentrating as do diabetics with extremely low blood sugars as a result of their taking too much insulin. Polio survivors often have a "Type A" diet, drinking three cups of coffee for breakfast, not having lunch and eating cold pizza for dinner. The Post-Polio Institute "Hypoglycemia" Diet, recommends about 16 grams of protein at breakfast as a long-lasting energy source, has been found to reduce many of the symptoms of post-polio fatigue.

POWER BREAKFASTS for Polio Survivors

A 150 pound person needs 70 grams of protein per day.

Polio survivors need protein in the morning for long-lasting energy.

So, how about getting 25% of your daily protein need met at breakfast?

12 minute breakfast	2 hard boiled eggs (12 g) and an English Muffin (4.5 g)
8 minute breakfast	3 scrambled egg whites (10 g) and a bagel (6 g)
6 minute breakfast	Toasted bagel (6 g), lite cream cheese (6 g) and 1/2 glass 2% milk (4 g)
4 minute breakfast	Yogurt (12 g) and 1 oz of low-fat cheese (6 g)
2 minute breakfast	1/2 cup low-fat cottage cheese (14 g)

Post Polio Network - Tasmania Inc

With encouragement, advice and practical assistance from the Victorian and New South Wales Networks, Post Polio Network - Tasmania Inc officially came into being on 18 May 1998. The Tasmanian Network has its base in a rural country town (Beaconsfield), with a population of approximately 1000 in its surrounding areas. Luckily, Tasmania is small enough to travel from one end to another in a day, which will assist the group in reaching out to polio survivors. So far, three support groups are up and running, and moves for a fourth in Hobart are in the planning. Chairperson Jan Wright [(03) 6383 1690] and Secretary Felicity Mainwaring [(03) 6383 1538] will be attending our *Conference* and *Support Group Conveners' Workshop* in Canberra on 29/30 August 1998. We are looking forward to meeting them.

Support Group Report

Bernie O'Grady
Support Group Co-ordinator : Post-Polio Network (NSW) Inc

Phone: (02) 9688 3135

Co-Conveners

Support Group Conveners need support themselves. In a Group, some people may feel that they would like to assist in the running of the Group, but do not feel they have the ability, and sometimes the confidence, to facilitate a Group meeting. Conveners always look for new ideas whether they be planning a meeting, organising a guest speaker, or arranging local publicity for the Group (and the Network). There are also times when the Convener is unable to attend a meeting, and the Convener would be grateful if another member could convene the meeting in their absence. It is important that Group members continue sharing, supporting and encouraging one another.

If this picture fits you, then talk to your Support Group Convener, and I'm sure he or she will have a smile all over their face when they hear your words of wanting to help. You or your Convener may contact me, and you will be posted a booklet which outlines the Network's guidelines in running a Support Group. There is provision at the back of the booklet for you to sign to say you would like to Co-Convene a Support Group. I'm naturally available to answer any questions you might have. Once you return the signed form to me, I will present it for endorsement at the Network's next Management Committee meeting.

Support Group Update

In the last Newsletter I mentioned that **Cliff Cook** of Tathra would soon be starting up a **Lower South Coast Support Group**. I am pleased to report that they held their first meeting at Tathra on 28 June, with four members attending, some with the help of family members. Everyone was excited to meet each other and most eager to share their polio stories. Their next meeting will be held at Yvonne Dunn's home in Broulee, on 27 September. If any members would like to join the Group, please telephone Cliff on (02) 6494 4113 or Yvonne on (02) 4471 5977.

Since the June Newsletter, the Network has been successful in having four members indicate they would be interested in starting up a Support Group in their area. The areas where new groups will soon be operating are:

Fairfield Support Group **Convener : Andreana Salapatis**

Andreana would like to make contact with members in the area to start up a Telephone Support Group. Please telephone her on (02) 9727 2323.

Hornsby Support Group **Convener : Kerry Jenkin**

Kerry is hoping to set up both a Telephone Support Group and a regular meeting Support group. She wishes to hear from members in her area who are interested in participating in either Group. You can telephone Kerry on (02) 9476 1468.

Manly Peninsula Support Group **Convener : Joan Clarke**

Joan would like to hear from members in her area who would initially like to join in a Telephone Support Group. Joan hopes that once the Group is established she will find a convenient meeting place for members to meet on a regular basis. Members can call Joan on (02) 9976 5442.

Upper Blue Mountains Support Group **Convener : Liz Lynes**

Please get in touch with Liz if you would like to join her as she sets up a Telephone Support Group. You can reach her on (02) 4788 1170.

Further details of these new Support Groups will be published once they get underway.

We still need Conveners for: Eastern Suburbs
Canterbury / Bankstown
Sutherland / Sylvania
Orange

If you can help, we'd love to hear from you.

Support Group Conveners' Workshop - Sunday 30 August 1998

Finally, I'd like to give one last reminder about this Workshop which will be held at ACROD House in Canberra on the day following the Mini-Conference.

We are very fortunate to have secured the services of Helen Prendergast to facilitate the day's proceedings. Helen is a trained teacher who in 1989 established a consultancy firm of project managers and independent researchers with particular expertise in social justice, access and equity, equal employment opportunity and anti-discrimination issues. She has conducted many seminars and workshops in these areas. Helen's demonstrated experience and, importantly, her good humour, will ensure we have a dynamic, productive, yet fun day.

The day will commence at 10:00 am and conclude by 3:00 pm. The Network's philosophy on Support Groups, how Groups fit into the Network structure, the roles of the Support Group Co-ordinator and individual Conveners, and how the Network may better serve its country members will be discussed. The Support Group structure has now been in place for more than five years, and it is appropriate to review the functioning of the Groups within the Network and discuss whether the guidelines under which Groups operate can be improved. A feedback session from participants will teach us what Groups are doing around the state, and what difficulties they encounter. We all have so much to learn from each other. From this open debate it is expected that strategies will be developed, or recommendations made to the Management Committee for further action, as appropriate.

Conveners from all over New South Wales have registered for this Workshop and we are very pleased with the level of interest shown. We will even be welcoming the President and Secretary of the newly formed Tasmanian Post Polio Network. This will be the first time many Conveners have met each other, and members of the Management Committee, in person. I know that I am looking forward to meeting everyone face to face at last.

Remember, there are still areas in New South Wales where a Support Group is not yet operating. If you would like to meet with fellow polios in your local area, attendance at this Workshop is a great way to find out how to start up a Group. It will also provide an opportunity to talk to members who are already successfully running Groups. If you would like to come along, please ring me as soon as you receive this Newsletter. Remember that attendance is free, and morning and afternoon teas and a light lunch will be provided.

Responses to "A Plea for Strong Lightweight Calipers"

Roger Smith's plea in the last issue of the Newsletter aroused quite a bit of interest from members. Thank you to the following people who wrote in with advice for Roger. If anyone would like to follow up on this advice, drop me a line and I'll put you touch with the writer(s).

In response to Roger Smith from the ACT re lightweight calipers (Issue 36, June 1998), I too went through the dilemma of what sort of caliper to order five or so years ago. I was experiencing great fatigue and back pain. I had heard of plastic moulded devices and also of the carbon fibre caliper. I had a plastic job made but could not learn to use it with confidence ("you can't teach an old dog new tricks" so they say!). I waited a few more years until the "bugs" were ironed out of the carbon fibre caliper before being measured up. My old caliper weighed 5 kg - a great lump to lift up with each step - no wonder I was fatigued and had back trouble. My new carbon fibre caliper weighs less than 2 kg - I learnt to get used to it real quick. My scoliosis has lessened (after new caliper and shoe build up), my back pain almost gone, and fatigue improved. The cost was around $1800 - I received $1000 refund from my medical fund.

Sue Ellis, Normanhurst, NSW

Re Page 15 of the June Newsletter - Roger Smith ACT, I have been so impressed with the personality of, and service given by:

Brent Sinclair
137 Quarry Road
Bossley Park NSW
Tel: (02) 9823 7711

to whom I was referred by Dr Katrak, that I rang him re Roger Smith's problem. He says much depends on Roger's weight but if Roger likes to contact him they can discuss - he is at present making an aluminium caliper as well as a stainless steel one.

Do hope something comes up for Roger Smith. Congratulations on such an excellent Newsletter as you produce - always a joy to receive.

Liz Lynes, Medlow Bath, NSW

I refer to the PPN Newsletter, Issue 36 of June 1998 and the letter from Roger Smith from the ACT regarding lightweight calipers.

As a metallurgist, I suggest that the manufacturers of calipers should contact *Comalco Technical Services* and discuss the availability of high strength, aluminium alloy tubing for the fabrication of calipers. There are numerous heat-treatable alloys, such as those used in aircraft construction, which would be suitable.

A design engineer (contact *Unisearch, University of New South Wales*) could also examine the feasibility of using a similar alloy for the manufacture of the joints. If machining costs proved to be a problem for these components, precision investment castings would obviate almost all machining.

I trust this information will prove to be helpful and should you need assistance in contacting relevant suppliers, please don't hesitate to contact me.

Lewis H Keys, Bicheno, Tasmania

POST-POLIO POST

We were saddened to hear of the death in April of long-time member Gordon Witts of Collarenebri, following an accident on his farm. Gordon was a great supporter of the Network and told his story to his local paper during Post-Polio Awareness Week in 1996 to help publicise the Network. Gordon's wife Shelagh recently wrote to me with a very generous offer. If any member could put Gordon's boots to good use please get in touch with me and I'll put you in contact with Shelagh.

Dear Gillian

I did appreciate your card.

After trying for years to find someone to make boots for him Gordon had finally collected a pair only six weeks before his horrific accident.

If there is a man who gets the Newsletter who could use a pair of tan elastic-sided boots, size 12, with the RIGHT boot built up 1-1/2", and deep over the toes on that boot, I would be happy to send them to him. Gordon didn't work in them so they have had so little use the soles are barely scratched.

David Luck's newspaper clipping prompted other members to put pen to paper about their hospital experiences. Thank you to member Nita Halsey, Port Kembla, for sharing her story with readers of this Newsletter.

Dear Gillian

In reading David Luck's letter in the June Newsletter, my mind goes back to when I first contracted polio myself. I had it in the right foot and ankle which is still giving me a lot of trouble now with post polio syndrome.

After spending quite some time in Prince Henry Hospital in 1951 when I was only about 8 years old, my brother who was older than I had it all over his body, arms and legs. He was about 14 years old. We were moved from hospital to hospital around the Sydney area together.

David's article certainly rang bells reminding me what a struggle our parents must have had at that time, especially when they had to travel to and from Mudgee to Sydney each weekend to see us, and not having any spare money because they had four other children at home to look after as well. I remember it being winter time and train travel from the country in those days was a nightmare as well as freezing cold.

All I can say now is I thank God that my five children were immunised and never got it.

Keep up this great newsletter.

POST-POLIO POST

As I read this letter from Central Coast Support Group Co-Convener Lynne Ellis, it evoked memories of my own time in hospital as a small child. I hope you enjoy Lynne's reminiscences as much as I did.

I was very interested to read the cutting from the 1951 Newspaper re overcrowded hospitals in the 1950-51 Polio Epidemic.

I contracted Polio in September 1951 and was sent to Prince Henry Hospital - I was there for the next 18 months!! They tried in vain to transfer me to Royal North Shore Hospital, my local hospital, as I lived at Killara. However there were no beds to be had there.

Interestingly, we were told that the majority of Sydney cases were from the North Shore and the Eastern Suburbs in that epidemic, and there were more teenagers and people in their early twenties than young children affected!

I spent most of my 18 months at Prince Henry in a 20 bed ward. The sister in charge was a real martinet, we were not allowed to have any personal possessions around us. We could have nothing except a bowl of fruit, or possibly (grudgingly) some flowers on our bedside lockers. Nothing else, not even a photograph! The lockers had a top shelf and then a cupboard, no drawers. Nothing was allowed to be stored on the shelf. So everything we needed, pyjamas, toilet requisites, bed jackets etc, had to be jammed into the little locker. As there were very restricted visiting hours, it would be days before we got clean pyjamas, so we needed to store several pairs. This meant that there was no room for a book, or knitting or any craft work we might want to do.

I was on a frame, with legs in removable plasters, wide apart ... so there was a certain amount of room on the mattress between my feet. So I stored quite a lot of things there!! Sister would have had a fit if she had known. But as long as the bed looked okay from the outside, she was satisfied, and the kind nurses never gave my secret away.

We were not allowed to have screens around the bed when using the bedpan either ... too much work for the nurses, she would say. Any modesty one may have had was soon dispelled!

We weren't allowed to have baths either. Again "too much work.....etc". After I had been there about 6 months, another sister who was relieving our sister said I could have one. They wheeled me out to a beautiful deep plunge bath, and two dear little nurses lifted me in ... I can still feel the absolute **bliss** of the hot water up to my chin!! Hair washing was also frowned upon, and had to be done (in a dish, in the bed, of course) when sister was off duty. Actually we even gave each other home perms from time to time, crossing over to another's bed on a bed table or illicit wheelchair!

I can't speak highly enough about the nurses, they were wonderful, and we soon became friends with some of them who used to come and visit us (when Sister was off duty!) after they had been transferred to another ward. The physios were good too, always doing extra-curricular things for us.

Visiting hours were only three times a week, Tuesday and Thursday nights for an hour, and Sunday afternoons for two hours. They were strictly controlled and the minute the hour was over and the bell had been rung, our visitors were unceremoniously herded out like sheep! It was a long way for my visitors to come from the North Shore to Little Bay, and not many had cars in those days, for just an hour's visit.

Quite often Sister used to stand at the door of the ward and announce "I hate Polios". She left us in no doubt that we were a dreadful nuisance as we couldn't move, had to be waited on, and should be in our own local hospitals anyway!! Shades of "abuse" (see Dr Bruno's recent article in the Newsletter *[Ed: Issue 36, June 1998]*).

There was no TV in those days and no radio in the ward. We had to make our own amusement ... at night we used to sing together. Our favourite song ... "Whispering Hope" ... led by little 8 year old Terry Fletcher, who had the most beautiful voice. I think it sounded quite lovely.