

POLIO NSW INC

formerly Post-Polio Network (NSW) Inc

NETWORK NEWS

Incorporating – Polio Oz News

Editors: Nola Buck and Susan Ellis
Email: editor@polionsw.org.au
Website: www.polionsw.org.au

PO Box 2799, North Parramatta
NSW AUSTRALIA 1750
Phone No: (02) 9890 0946

Patron: Professor Emeritus Sir Gustav Nossal AC CBE FAA FRS

President's Corner

Gillian Thomas

At our 24th Annual General Meeting held on 30 November 2013 the following members were elected to the Management Committee:

Gillian Thomas	<i>President</i>	Nola Buck
Susan Ellis	<i>Vice-President</i>	Barbara Fuller
Merle Thompson	<i>Secretary</i>	Gary Fuller
Alan Cameron	<i>Treasurer</i>	Alice Smart
Charles Anderson		John Tierney
Anne Buchanan		

We were sorry to say good-bye to Wendy Davies who decided to stand down from the Committee this year to pursue other interests. We will miss her sharp eye for detail and her input at Committee meetings. Wendy's departure means we currently have a casual Committee vacancy as her position was not filled at the AGM. If anyone is interested in offering their skills and experience to the Committee by filling this vacancy we would love to hear from you. Just contact me, or George in our Office, for more details (contact details are on p 18).

The Seminar following the AGM was presented by a volunteer from the Black Dog Institute, Anne Reddacliff, who spoke about "*Breaking Down Depression and Building Resilience*". Her presentation was very well received and generated a lot of questions which were expertly answered. Sue Ellis will be writing up the Seminar Report in the next issue of *Network News*.

On pages 5 to 15 of this *Network News* you can read the concluding chapters of Sue Ellis' Seminar Report on Dr Peter Nolan's comprehensive presentations at our 2012 AGM. Writing this Report (the start of which appeared in *Network News*, Issue 87, pp 13-19) has been a mammoth undertaking and we hope you gain a lot from it. The videos of the presentations can be accessed at www.polionsw.org.au/seminar/nolan.

The 2014 Polio Health and Wellness Retreat will be held at *St Joseph's Centre for Reflective Living* in Baulkham Hills, NSW. The dates are Thursday 8th May to Sunday 11th May. Polio Australia held its first Retreat at this venue, which is a lovely, peaceful environment, and very conducive to sharing and learning new information. If you are not already on Polio Australia's email list to receive registration and other information when it is sent out early in 2014, contact the Polio NSW Office or email office@polioaustralia.org.au.

We are keenly aware that many of our members are no longer able to either use public transport or drive themselves to Seminars, Support Group meetings, and other Polio NSW activities. Through the Federal Government's *Volunteers Grants* initiative, we have obtained limited funding for fuel for a volunteer to drive members to/from these activities. If you can arrange for a family member, friend or neighbour to drive you we will give that person a \$20 fuel gift voucher (higher amounts will be considered for longer distances). If you could benefit from this assistance please be sure to contact the Polio NSW Office for more information.

Next year marks the 25th Anniversary of Polio NSW and we hope you will celebrate with us – further details will be advised in the next issue of *Network News*. In closing, the Management Committee joins me in wishing each and every member and your families a joyous Christmas and a healthy New Year.

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Support Group Report

by Gary Fuller, Support Group Co-ordinator

Port Macquarie Support Group

Gail Hassall who has been Convenor for 4 years tells me that the Port Macquarie Support Group had its first meeting in November 2003. The Group was set up by Pat Adamson who was Convenor until she left Port Macquarie in 2009.

The Group is to celebrate their 10th Anniversary at their December Christmas Meeting.

The Group is likely to soon change their name to “Mid-North Coast Support Group” as members are drawn from Foster, Kempsey, South West Rocks and Bowraville, as well as from Port Macquarie. The new name will therefore reflect the areas from which the current members are drawn.

Nepean Support Group

Member Madeline Coelho of Springwood read in the September *Network News* that we were seeking a Convenor for the Nepean Support Group and let us know that she would be interested in taking on this role. Madeline has not let the grass grow beneath her feet and has already organised the first meeting. It will be held on Monday, 17 February 2014 at the Penrith RSL Club (8 Tindale Street, Penrith), commencing at 11:30 am, followed by lunch (own cost). If you live in the Nepean area and would like to come along to the first meeting of this Group, please let Madeline know – she can be contacted on 02 4751 1272. Following the initial meeting, it is expected that the Group will continue to meet at this venue on the third Monday of each month throughout 2014.



Your local Polio Support Group needs you. If you are not in a Group then you do not know what you are missing!

Gary Fuller is your Polio NSW *Support Group Co-ordinator*, with the assistance of Barbara Fuller who actually is the polio survivor.

Our job is to provide a link between the Committee of Polio NSW (we are both Committee Members) and the Convenors of the twenty two Support Groups in New South Wales and the Australian Capital Territory. Barbara and I are always available to provide practical assistance and advice to Convenors if they ever need it.

Polio NSW set up a network of Support Groups throughout NSW in 1992. One of the aims of Polio NSW was to provide a supportive framework of assistance for polio survivors – the creation of Support Groups was one of the strategies developed.

We believes that this has been successful, Barbara has experienced very good advice and a tremendous amount of practical help from fellow Support Group members, in the short time she has been a member.

A complete list of the Support Groups, their Convenor and contact phone numbers was listed in the September *Network News*.

Membership of a Support Group puts you in regular contact with people who share similar problems and experiences. Members provide assistance to one another through their

shared polio history. Each individual brings a range of strategies which they have developed to assist them cope with the challenges of everyday living. The sharing of these resources can assist all members of the group. Membership of a Support Group will enable you to develop new friendships, provide a support circle of Polio NSW members to help you cope with the late effects of polio and give individuals the opportunity of taking a more active approach to living with polio.

We do what we can to help new members join a Support Group in their local area and also foster the establishment of new Groups. At the moment we would like to see this happen in Dubbo and in the Blue Mountains.

So at any time feel free to get in touch with Gary or Barbara Fuller. You can ring us on 02 9523 2428 (has a good answering machine at all times), write to us at the Polio NSW Office, or email us at supportgroups@polionsw.org.au.



*In Memory of
Mary Le Clair*



On Saturday 26 October, approximately 200 people attended the fundraising concert for Polio NSW at Parramatta Leagues Club in memory of Mary Le Clair.

We were entertained by Lisa Budin, Francesca Brescia, Kristy Lee, Roseanna Gallo and George Vumbaca. The band kept us all 'bopping' as we enjoyed all the songs of the 50s, 60s and 70s. We were treated to Lisa singing the Carpenter's songs and guest spots by Roy Orbison and Elvis were highlights as well as songs from Sister Act performed by the entire cast!

Jace Pearson, the compère extraordinaire, kept everyone mesmerised with his incredible yodelling talent and his infectious 'sparkle'. Lisa, with her band of helpers, including family members, truly provided us with a fantastic night.

The evening was topped off with a huge raffle of donated prizes, organised by Lisa and drawn by Jace.

The Committee would like to thank Lisa and all those who gave of their time to support Polio NSW and to celebrate the life of Mary Le Clair. A great night was had by all!!!



A Post-Polio Approach to Bushfires

by Ben Tipton

Ben is a retired professor from University of Sydney, originally from the United States and a long-time resident of the Blue Mountains. He attends the Hills District Support Group. During the recent fires Ben kept support group members up to date with events and entertained us with some humorous stories and now has some advice that we could all benefit from as polio survivors.

As a survivor, now three-fold, of bushfires in the lower Blue Mountains, it occurred to me that some of what we have learned may be more broadly applicable. Fires are not the only sort of emergency that confront us. We each, I think, have our own personal worst case scenario. The question I have posed myself in the aftermath of the fires is, am I, or rather are we, my wife and I, ready for those other sorts of emergencies? Our answer is, broadly, yes, partly because of the bushfire experience.

Thursday – I see ugly columns of smoke to the north, driven east to west by high winds. My wife is overseas, our daughters live in Melbourne; I am alone. Previous experience, close encounters in 1994, 2000, and earlier this year, tell me that this is dangerous. From the deck I can speak to my neighbours on both sides, sensible strong guys who will defend their houses. I remind them that my plan is to evacuate. I take the emergency box out of the closet in our bedroom and work from the rear of the house forward, packing. I receive the emergency call from the RFS, but I wait until a police officer knocks and advises me to leave. I agree, and ask him to tell my neighbours that I have left. He carries the box to the car for me, and I lock the house.

However, the police officer has no suggestions when I ask where the “safer place” is for our neighbourhood. I drive to our local shopping centre. There is a community church, with toilets, and a supermarket. However, in 2000 this centre was under threat as well. My plan is working, but there is a gap, a rather major one – I have no place to go.

The initial fire passes to the north, and the Police allow us to return (*many of the cars have dogs in the rear seats, and one lady has a bird cage beside her in the front*). However, the fire continues to burn to the north and west, an orange glow through the night. Daylight, and a continual convoy of helicopters carrying water to the burn just over the crest of the ridge. The RFS updates on their website are very good, but of course hours behind. I am fortunate; our lovely views also make us an ideal spot for the RFS to set up, and I hear their orders back and forth through the loudspeaker over the entire weekend.

Friday night – a crew from Canberra lights a back burn beginning at our rear fence. There is a lot of smoke, and I retreat inside. The house is smoky despite being closed; if I suffered from respiratory problems, I should have left when I was informed of the back burn. During the night the wind shifts, and our roofs are sprayed (*one of my usually sensible neighbours is drenched; what he was doing in his backyard at that point remains a mystery*). I have brought the emergency box back into the house, but left it by the front door, and left the external shutters down. Saturday – the fire in the northwest and the back burn in our valley continue to burn, but the immediate danger has lifted.

Sunday – helicopters put water on two stubborn pockets, one from the original fire and another from the back burn. My neighbours across the road see this, panic, dial 000, and order an emergency vehicle to come to pick me up. I have an amusing conversation with the driver while his partner calms my neighbour in the street. Another gap in our plan, however; we had not consulted in advance with *all* our neighbours.

And so it goes for the next few days, monitoring the RFS site, waiting to see whether the main fire can be contained, and still packed and ready to leave if necessary. I have received offers of accommodation (thank you, Sue Ellis!), but clearly this was the major issue we had not considered, and thinking about that got me to thinking about other sorts of emergencies. Everyone will have different needs, and a different way of approaching a crisis, but the essential thing, I believe, is to have thought it through clearly beforehand, and to have a guide, a list of things to do, that you can follow. In a crisis you make mistakes. We have friends who lost their house; the husband saved the sterling silver, but forgot his wallet in the rush. Equally important, if you are incapacitated, a clear list gives those who assist you a program to follow.

So, our bushfire plan is to evacuate. Start early, the less mobile you are, the earlier. Consult with your neighbours. Get dressed, shoes, long sleeves, keys, wallet (*including list of medications, and alerts of my pacemaker and post-polio status*), watch, phone. Lower the shutters, and bring flammable objects (*gas bottle for BBQ*) inside, if there is time. The emergency box includes fire-specific items (*face masks, gloves, water bottles; see www.rfs.nsw.gov.au*), but also more general things (*toiletries, changes of clothes, towels*). We have plastic bags for the items to be added. From the rear of the house, in the bathroom, our prescription medicines; in our bedroom, clothes, repeat authorisations for medicines, phone chargers, chequebooks, documents (passports); from our studies, the backup drives for our computers. I keep an address book with phone numbers, but also usernames and passwords, particularly for our bank accounts. There is a list of all our credit cards, in case I should lose my wallet. You may have a file including the photographs of all the rooms of your house, in case you need to document your losses for the insurance company.

For us, it is fairly easy to generalise these preparations. We let our neighbours know when I will be alone, and I always carry the alarm remote with its panic button, so they can assist if necessary. If one of us were injured or ill, the list of items inside the emergency box can serve as a basis for assistance as well. Neighbours or emergency workers can use that list, and you will arrive at the hospital, for instance, with all of your prescription medicines and the repeat authorisations, plus a change of clothes, and your phone with charger. You never know. Our main concern is the possibility of my having a fall while home alone, of course. However, recently my wife woke in the morning with a severe attack of vertigo, virtually totally incapacitated. If she had been alone, then our plans would have helped to see her through.



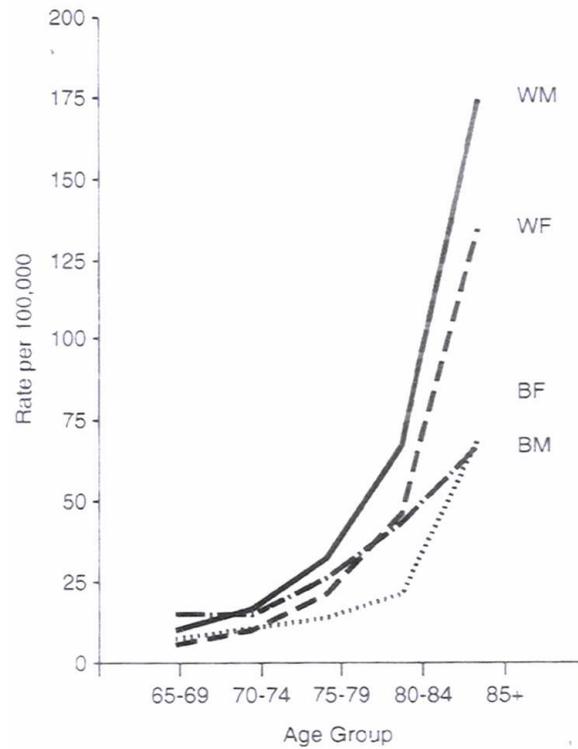
Seminar Report - AGM 8th December 2012

by Susan Ellis, Seminar Co-ordinator

The following is the remainder of Dr Nolan's first session which covers the ageing process and falls. This is followed by his second session titled, "Cough, Spit and Breathlessness".

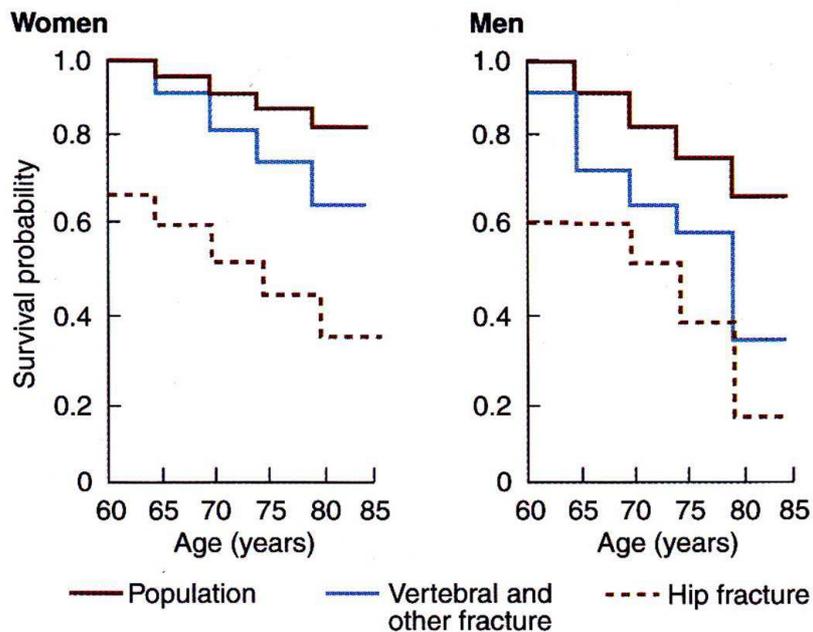
The Bones Beneath: Ageing, Bending, Breaking

The greatest risk to having a fracture is AGE and the incidence of fractures increases dramatically after 65, earlier in women than men because of post-menopausal osteoporosis.



Mortality after a fracture: as we age, the likelihood of surviving a fracture diminishes. An 80 year old who falls and fractures a hip has only a 20% chance of being alive one year later. That is how dangerous, how physiologically severe, a fall and a fracture is. There is only one treatment of a fracture and that is PREVENTION and a prevention strategy of things to think about, and discuss with your GP, should be formed. Dr Nolan's advice is that we cannot afford to let a fracture happen.

1: Cumulative survival probability after fracture

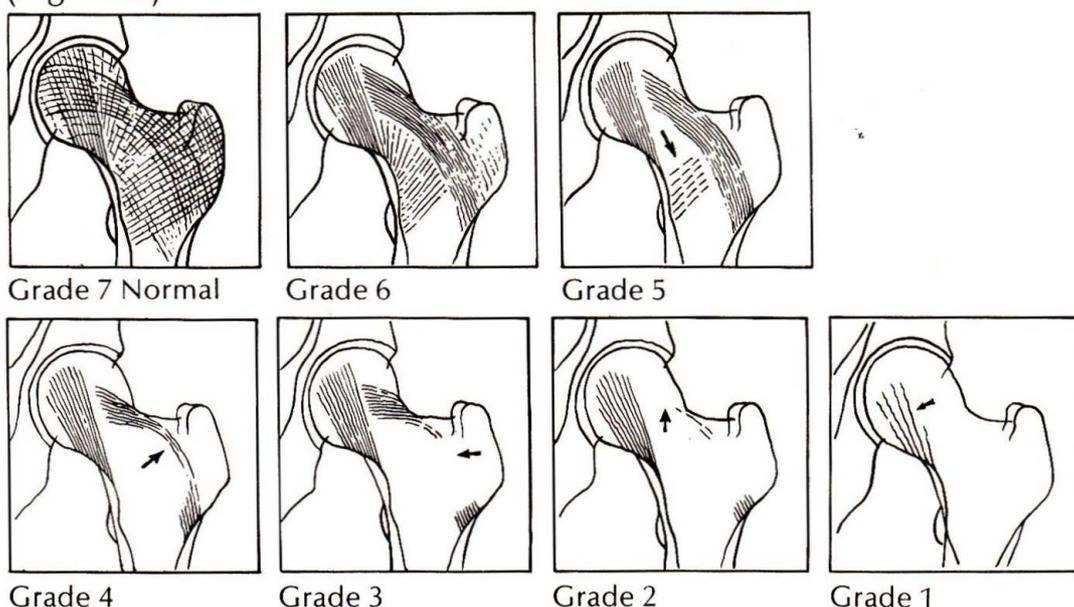


Survival is reduced after any type of fracture, vertebral or non-vertebral, more so in men than women. (Figure reprinted from Center et al⁴ with permission from Elsevier.)

Dr Nolan explained that walking is a very complicated process, affecting our balance and the centre of gravity and in most polio patients our walking is NOT NORMAL. Even if you don't have significant weakness, you have started with an altered centre of gravity which then affects your standing balance, so you are already a risk patient because of abnormal standing balance. This is why, even without significant weakness, we have a greater risk of falling. In addition to balance, add a minor aberration in a footpath and you are over. This is why there is more to it than just what we are doing but it is the physical environment that also places us at risk.

Osteoporosis: Osteoporosis is where the trabecular thins and contains less bone. There are two types of substances: there is the tissue component called osteoid, the hard component which is the bone, and inside that is the marrow.

Trabecular Grading Patterns (Singh) (Figure 2)



The protective girdering which is there to protect and support our hip progressively fades, which places the neck of the femur at greatest risk of snapping – it doesn't take much of an injury when the bones are that weak for it to just snap!

The imperative to treat increases with:

- Increasing age
- Declining BMD
- Prior fracture
- Family history of osteoporosis
- Risk factors for bone loss (eg, hyperparathyroidism, corticosteroid therapy, immobilisation, chronic illness)
- High levels of bone remodelling markers

Bone mineral density is evaluated by DEXA (Dual Energy X-ray Absorptiometry), performed on two areas, usually the spine plus right or left hip, two areas with best normal values and two areas of commonest fractures. Medicare rebates are given to those over age of 65 and/or having any concurrent illness and/or any history of a minor fracture.

Our “T Score” compares us to a healthy control (a person under 50 of the same gender). Osteopenia is thinning of the bone. Osteoporosis is more severe and means the bone is significantly less dense than the average healthy control.

The risk of a fracture significantly increases with increased reduction in bone density.

A study in Toowoomba in 2010 performed DEXAs over a period of one year on 22 polio patients with a history of falls or fracture. It was found that there was a dramatic difference between the polio limb and the non-polio limb. The polio limb was 4 times less dense than the normal healthy control, whereas the non-polio limb was 1.5 times less dense.

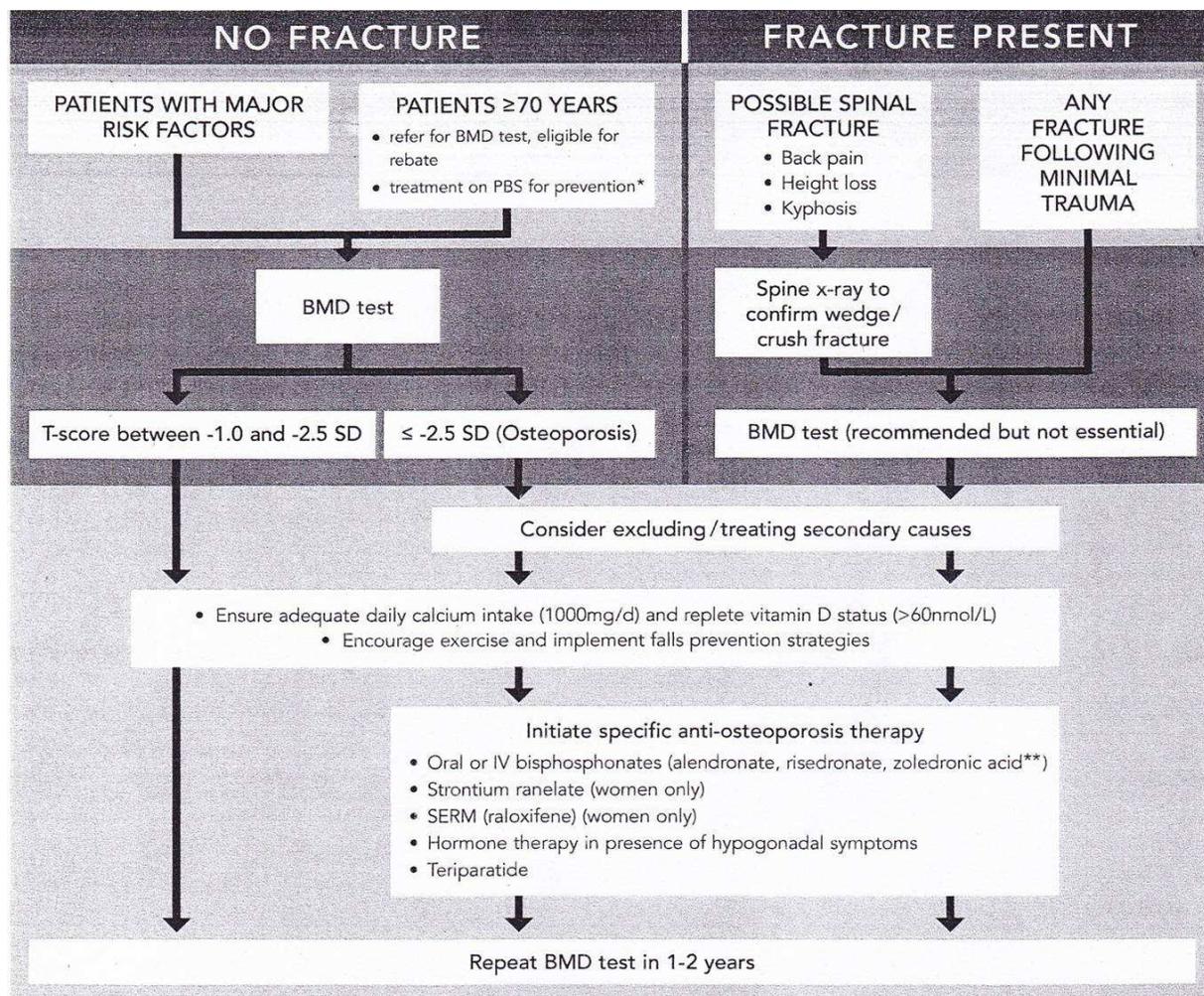
Why is that? The reason for this is that our bones are only as strong as our muscles. The muscles create the tension on the bone that tells it to regrow, to remodel, to develop. With polio the muscular strain (strength) is gone causing the bones to waste more rapidly.

Conclusion: Osteoporosis is highly likely to be very common in polio patients, with polio limbs being more severely affected. **It is for this reason that you must insist on the hip of your polio-affected leg being tested for osteoporosis.**

What can we do?

Vitamin D replacement is very important for the prevention of fractures and when we look at why, it actually reduces falls. It is not just for the bones but also helps stop the falls, vitamin D is important for muscle strength and the maintenance of muscle tone. Dosage 1000 iu daily.

Damage control:



Osteoporosis is an increasing problem in all diseases in people over 65 and there are set strategies to deliver treatment. These should be discussed, along with concerns about falls and fractures, with your GP. Treatment depends on age. There are lots of therapies now available including drugs, vitamin D, calcium supplements and many others.

Other issues that impact:

Drug Therapy: As we age, we consume more medications and we are more likely to have more than one chronic illness. We also have to be aware of the risk of error. The more medication you take, the more likely that an error will be made by you, by your pharmacist, or by your doctor, as well as the likelihood that the medications will interact with each other.

High Risk groups:

Age >85
Chronic renal impairment
Dementia
Peripheral neuropathy

All of these cause an increase in disability. A person with a chronic illness should have a clinical review every two years – a one-hour review to maintain and keep on top of what is happening.

Surgery:

You need to have an advocate for when you end up in hospital. The reason being that complications are common, the development of confusion as we age increases, and the likelihood of a smoother outcome is much better if someone understands that you have had polio, even though you have lived with it for 40-50 years. They need to understand how it could impact on you now with the drugs of anaesthesia, with pain management or with your post-op chest care. The ideal person for this advocacy role is your GP who will keep your doctors informed of your issues related to polio.

Legal Issues:

Issues of competency and autonomy
Maintaining a driving licence
Defining our independence concerning end-of-life issues

These are issues that we all need to sit down and think about and have some idea or framework in place. At the very least have those who are closest to you to speak on your behalf; if you were unable to speak they could share that responsibility, because at the very last moment in your life you do want things to be done right for you. The only way that you can really have that happen is if you can voice that or someone can voice it for you, otherwise decisions might be made that are not in your best interest.



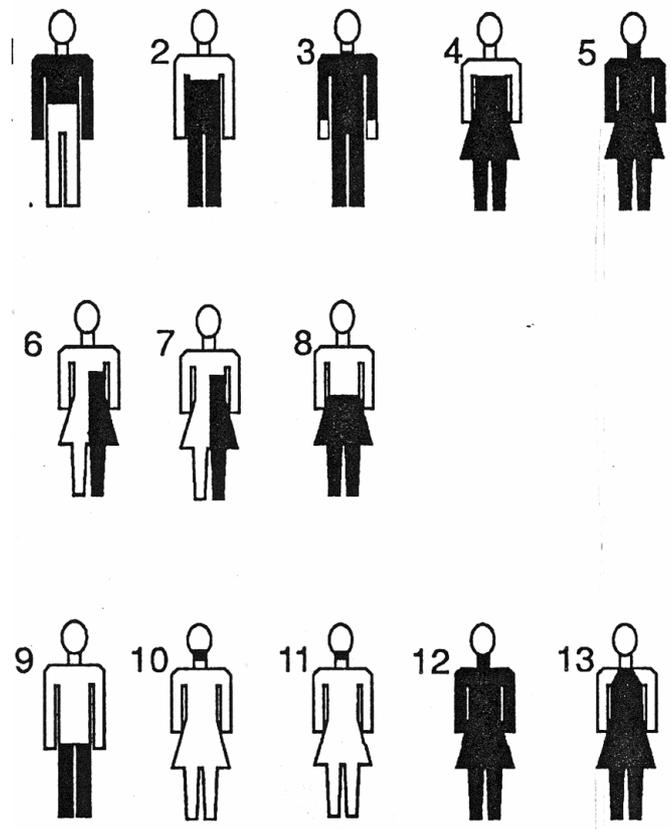
Cough, Spit and Breathlessness

The lung is best thought of as a system in series – if there is a problem at any one level then it can impact on the function of breathing.

It was in the early '70s that the whole issue re-surfaced of breathing problems affecting people with previous polio. Christian Guilleminault from Stanford University worked on measuring breathing during sleep because polio people were complaining of having difficulty breathing at night and were waking up feeling awful. That was the beginning of our understanding of the fact that the upper airways are so important in the function of ventilation when we are asleep.

When awake we are less likely to be affected because our muscle tone in our upper airways is maintained by voluntary control; but when we are asleep we are reliant on automatic functions and so are in a position of compromise. When we lie on our back or side, our diaphragm is displaced and our diaphragm does 70% of our inspiratory breathing function. In addition to that, our upper airway starts to relax and collapse down and, if it is already narrowed, it could close during those phases of REM (rapid-eye-movement, deep sleep), where the whole body is virtually paralysed, except for the eyes and the diaphragm – this is to ensure relaxation so our muscles can recover.

Guilleminault started actively reviewing polio patients and he found that there were variable risks for people who were having breathing problems:



In the early phase of their polio, those in groups 1-5 definitely had breathing problems involving their chest and diaphragm and required some degree of mechanical ventilation but then recovered. Then as they aged and as post-polio sequelae occurred and muscles weakened subtly, breathing problems only affected them when asleep.

The second grouping 6-8 experienced no problems at all, they had lower limb disease and no breathing problems at the time and they had a normal sleep study. If they did have a sleep disturbance it was more likely to be due to irregular leg movements and/or fidgetiness which we now call the syndrome of Periodic Leg Movements (PLM) during sleep which has a greatly increased incidence in polio. It can be caused by a spinal nerve irritation and can manifest as sleep disturbance – the partner in the bed usually reports this activity.

The third grouping 9-13 did not need ventilation initially, had no respiratory problems, but they all had some throat problem at the time, requiring artificial feeding with a naso-gastric tube or had choking occasionally. These people also developed obstructive sleep apnoea and needed later treatment in order to protect the airway during sleep.

A Western Australia survey of 230 polio patients, of whom 206 had sleep studies, found that there were four most predictive factors of sleep-related sleeping problems:

- A previous history of mechanical ventilation
- Current disability requiring wheelchair use for more than 50% of the day
- Previous history of naso-gastric feeding or upper throat swallowing problems
- Static lung function (breathing test done in GP surgery) less than 50% of normal

The three most common symptoms that people with sleep disorders report are:

- Disturbed sleep
- Day time tiredness
- History (from partner) of habitual snoring or guttural type noises or choking noises during sleep

There are many sleep medicine clinics throughout Australia who provide appropriate care for people with polio with all levels of breathing related problems.

In the normal population, 60% of men between 20 and 65 snore and only 30% of women; of the 60% of men who snore, approximately 18% of them have obstructive sleep apnoea. Of the 30% of women, only about 8% have sleep apnoea. Therefore, a male is more likely than a female to have sleep apnoea. Contributing factors include: men are generally heavier and more men smoke (although more women actually smoke now); alcohol consumption is higher in men than women. Alcohol is a significant modifier of airway function when we are asleep as well as brain recovery.

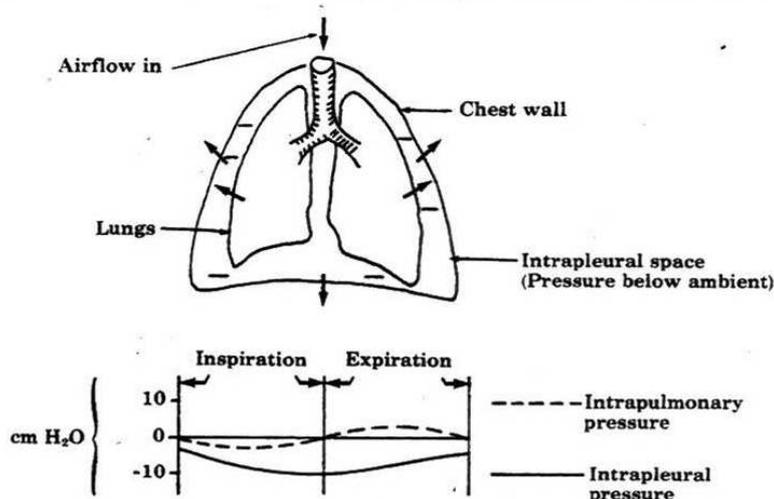
It was also found that polio survivors' incidence of breathing problems was not gender biased, it was more based upon previous history and current disability. It was found, however, that there was a definite relationship between body weight, and if you have a BMI greater than 30kg/m² then you were at greater risk of developing sleep apnoea.

So where is your diaphragm? It is at the top of the bottom-most rib that you can feel at the centre of your chest when sitting. When lying down it is at the level of a male nipple, it rises about 10 cm when you lie down which means you lose that volume for ventilation when you are asleep. If you then compromise that further, by adding another strain or resistance on the breathing system, then you are in trouble.

An analogy of how these systems are all connected is to imagine a tightly-coiled spring with a weight on the bottom, and then add further weights to see how far they would stretch. This is one way to think about what it is like to breathe. To breathe, the energy expended occurs only on inspiration, because our lungs are elastic and they will recoil on expiration – as you breathe out, the lungs will spring back. So our greatest challenge is to use energy efficiently to breathe in. If you put a series of springs one after the other it is going to be much harder to stretch the springs. Similarly, if we have the throat, the airway, the diaphragm and possibly what is below the diaphragm (eg 40kg of fat which needs to be pushed out of the way), then you have about four springs in a row which makes it almost impossible, especially when you are asleep and relying upon the automatic system to perform that process.

What side is best to lie on? It is better to lie on the right side; you get slightly better ventilation, whilst on your back you snore. Lying on your back can obstruct your airway.

Guilleminault became aware of breathing problems, mainly at night, because of the development of sleep medicine. Respiratory failure is when you don't maintain adequate oxygen levels or normal carbon dioxide levels. If your oxygen level is less than 60mm of mercury, or carbon dioxide greater than 50mm, then the system is in respiratory failure. It was found that with polio patients who were in respiratory failure, the problem could be traced back to what was happening during sleep. It was found that if the night problem is treated and reversed then the patient felt better during the day and could maintain normal oxygen levels during the day because the muscles worked better when awake and alert.



Mechanics of breathing: The upper airway is where the main problem of sleep apnoea occurs, then the central airway, the driving pressure or the pump, and then we have what is below the pump, so if there is displacement required of abdominal content that can add to the strain.

There is a high correlation between swallowing problems and sleep apnoea and it is recommended that tests should be performed to localise the problem. A swallowing problem occurs when there is a weakness of the crico-pharyngeus muscle (a trapdoor at the top of the gullet) which is used to stop food from regurgitating or going down too early before being masticated in the mouth. This is diagnosed by doing a video swallow – this is not a normal barium swallow but a continuous video film from the mouth down past the throat, performed by a speech therapist in an x-ray department whilst trying different consistency of foods. ENT clinics and/or speech therapist services will perform this study.

As there is a high incidence of reflux disease in post-polio a dynamic study is needed: *the water siphon test*. If the swallow study looks normal then while lying down with barium still in the abdomen, sip water through a straw - this can precipitate acute reflux right up and into the larynx and into the lung causing mini aspirations. This test localises where the problem is. There are various treatments available.

What was found in WA is that the ageing process, ie the weakness and disability that will happen to us all as we age, starts earlier in polio patients and predominantly manifests as a weakness of muscles.

Could we find any evidence that the polio patients' breathing muscles were weaker? A study was done looking at how many years since the onset of polio and how breathing muscle strength compared to 1,000 normal controls of the same age. It was found that the

breathing-out and the breathing-in muscles of the polio patients were falling by 7% per year greater than the average loss of power of a non-polio patient. So even if your primary illness didn't specifically involve your diaphragm, as a group there appeared to be slow deterioration of breathing muscle strength with age and it seemed to slowly progress with aging, starting around 20 years after the onset of polio.

It is felt that probably everyone with previous polio should have breathing muscle evaluation and if there is any evidence of a fall in muscle function, ie below or around 50%, then have a diagnostic sleep study.

COPD (Chronic Obstructive Pulmonary Disease)

There are two problems that can occur with the airways. The elasticity of the lungs is impaired, ie the tubes might be alright but the lungs don't empty properly, OR the airways might be severely impaired, thickened and narrowed and we can't get the air through.

Types of airway disease: Emphysema, chronic bronchitis (inflammation), bronchiectasis (chronic inflammation with damage and chronic infection), intermittent obstruction (later onset asthma), environmental exposure.

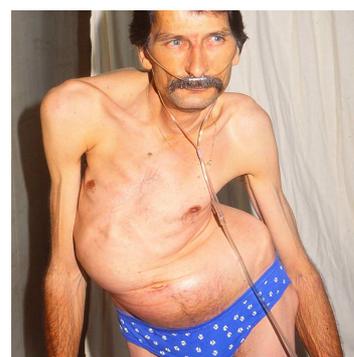
If you already have mild upper airway weakness and then add to that lower airway disease then it will be harder to breathe and then you become more symptomatic. To measure for impaired weakness your GP can use a spirometer. If there is impairment then there is airways disease and you need various treatments.

The most common cause around the world of lung damage is by fossil fuels ie cooking on an open fire, inhaling fossil-fuel smoke, it is far worse than cigarette smoke. In 1945, 75% of adults smoked and now it is only 21% – unfortunately 54% of these are women. Now more women die from lung cancer than from breast cancer. There is nothing good about a cigarette. There are also more and more instances of lung disease from passive smokers, people who have lived or worked with a smoker.

Other causes of lung disease: Airway irritants – Work related: freezing fresh fish using monosodium glutamate which can destroy lungs through chronic asthma. Recreational: Mulch on gardens – 20% of people are allergic to a fungus (aspergillus) which can also be found in potting mix and can precipitate acute breathing issues. It is recommended to use a mask when using potting mix and work in a ventilated area.

Worldwide, COPD is the fourth leading cause of death. It was found during the investigation of breathlessness in WA that 25% of polio people who suffered with breathlessness had unrecognised airways disease. Polio itself doesn't affect the airways but recurrent aspiration affects the airways, ie burning of the airways, and some people with uncontrolled reflex and pharyngeal problems can also cause a problem. For most of these people it was an acquired disorder on top of their polio that was compounding their breathlessness.

Co-morbid disease: A polio patient with chronic kypho-scoliosis, which effectively squashes the lungs, has an increased risk of breathing problems. The chest wall over time becomes rigid and the patient cannot expand the chest wall which means the lungs cannot expand.





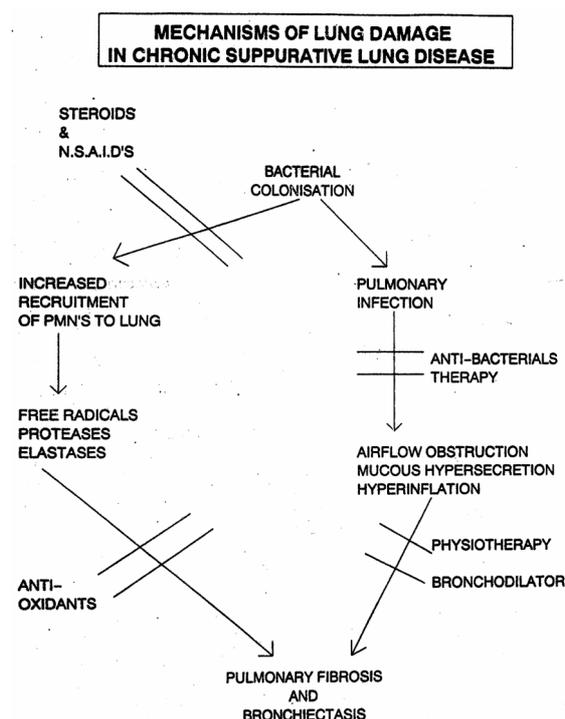
Obesity: Lungs can also be squashed due to being overweight. The diaphragm is elevated way above the nipples because it is being compressed by a large abdomen. Generally, pear-shaped obesity (mainly around hips and upper legs) has no respiratory consequences and actually has a lower incidence of heart disease whereas apple-shaped obesity (around the abdomen) is bad for breathing and bad for the heart. A personalised program with a realistic goal of a 10% weight loss in 12 months is recommended. Incremental advances moving towards a more healthy weight range will have a sizeable impact on the breathing ability.

Evaluation of the upper airway can be made simply by looking into the mouth, with the tongue poked out, and if you can see down the back of the throat there isn't a blockage to air but if you can't see past the tongue then there is a big blockage to air. There is a scoring system of 1-4 which can be used to determine who might be at risk of breathing problems.

If you have got respiratory muscle weakness or airway disease at any level you are at a higher risk of developing an acute infective exacerbation and need to have a preventative and emergent plan in the event of infection.

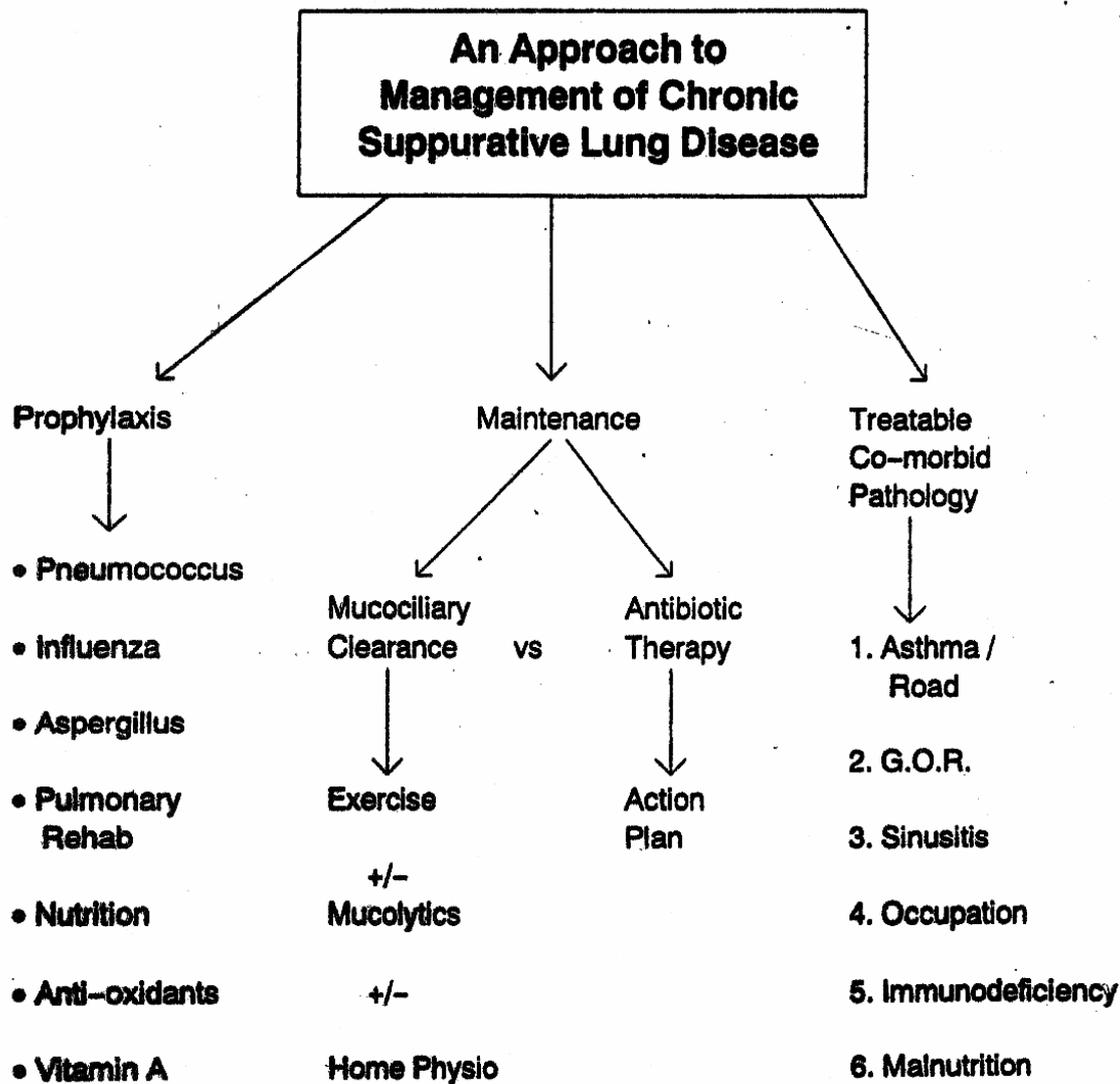
What can we do? If you have respiratory problems with polio you need to have a breathing test, address the issue of exposures at work or recreation (eg potting mix), stop smoking, eat properly (not to be too thin and undernourished or too fat), exercise (a balanced approach), optimise activities of daily living (ADL) (don't exhaust yourself, do things smarter rather than harder), have a regular medical review, and early intervention with acute illness.

For anyone with previous polio and respiratory problems if you develop flu-like symptoms and you fail to improve within 48 hours then you must see your GP. The earlier intervention is sought, the better. If pulmonary infection and airflow obstruction is not controlled it becomes a repeating cycle. Recovery should be complete within 6 weeks.



General approach to people with chronic lung disease:

- Vaccination for pneumococcus and influenza
- Therapy and rehabilitation
- Avoiding exposure to aspergillus
- Exercise is the most effective way of keep mucous out of the lungs, and add to that inhaled saline
- Check for other related issues, eg untreated asthma, sinus disease, reflux, GOR



A Last Plea from Dr Nolan:

As a group, continue to expand the understanding within at least the medical community and if possible as well within the wider community.

Don't ever underestimate your own personal story and its ability to create change, to inspire, and to have impact.



Day Tripper

by David Stern, Senior Information Officer, Spinal Cord Injuries Australia (SCIA). Reprinted with permission from SCIA's "Accord" Newsletter, Winter 2013.



Garden of Remembrance, Rookwood Cemetery

Most people only visit a cemetery for the funeral of a family member or friend, or on important family and communal anniversaries. Cemeteries, however, also tell us a lot about our heritage, history and culture.

By the 1840s, Sydney's Devonshire Street Cemetery was close to being full so another larger site was needed. In 1862 the government purchased 80 hectares from the estate of Edward Cohen. The site was chosen for its relative isolation and proximity to the new railway line to Parramatta.

Rookwood Necropolis has become the largest cemetery in the southern hemisphere, stretching over 300 hectares. Over a million people are buried there, including some of Australia's most notable figures. Among them are:

- respected statesmen such as NSW Premiers Jack Lang and Joe Cahill, and Australia's first female Mayor, Lilian Fowler;
- leading business figures James Toohey, David Jones, John Fairfax, John Gowing and Bing Lee;
- notorious characters such as Jimmy Governor, Abe Saffron and Sally Anne Huckstepp;
- arts personalities including the poet Kenneth Slessor, and the songwriter of Advance Australia Fair, Peter Dodds McCormick.

Other notable 'residents' include well-known Sydney eccentric Bea Miles, suffragette Louisa Lawson, and James Calvert, a member of explorer Ludwig Leichhardt's first expedition into the interior. The epitaph on the grave of Jacob Pitman, the advocate of shorthand, is written phonetically, describing him as an "arkitekt" who "introduist fonetik shorthand".

There are many specific memorials that commemorate significant events and groups. These include the Sydney War Cemetery and Garden of Remembrance, a Holocaust memorial, and the Circle of Love which is a shrine dedicated to stillborn children or those who died in young infancy.

Tours of the cemetery are run by the Friends of Rookwood. Themed tours include Tales from the 20th Century, Plague and Pestilence, Ships and Shipwrecks, Murder and Mayhem, 19th Century Sydney, and ANZAC and Convict Heritage.

For more information on the tours visit <www.friendsofrookwoodinc.org.au>. Although the tours are not recommended for wheelchair users, the Friends of Rookwood will provide a guide to the points of special significance for a self-guided visit.

There are accessible toilets at a number of locations in the grounds of the cemetery and at Reflections Café. For more information on Rookwood Cemetery, visit <www.rookwoodcemetery.com.au>.



We have had a suggestion relating to the Post-Polio Health International document on Anaesthesia by Dr Selma Calmes which was distributed with the September issue of Network News. Member Dr Ian Neering, past Associate Professor of Physiology and Pharmacology at the University of NSW, has previously written articles relating to this subject in Network News (Issue 64, June 2004, pp 9-11) and in Polio Oz News (Volume 1, Issue 2, September 2011, pp 7-9).

Dear Nola and Susan

Congratulations on another bumper issue of *Network News*.

I was particularly impressed with the single page document detailing issues related to anaesthesia of polios. That will be a very useful addition to your other major document. Might I suggest a small addition if or when you revise the document? Anaesthetists are often required to monitor blood gases during or after surgery. With post polios, especially those with long-term respiratory issues, PaCO₂ (arterial carbon dioxide levels) may be permanently elevated. The body of such polios has become acclimated to these levels and the polio person notices no deficit related to the higher CO₂ level, that is, this is normal for the particular person.

Anaesthetists tend to work by the numbers and, if they see elevated CO₂ levels, they are likely to keep a patient connected to the ventilator for much longer than necessary. If this is likely to be an issue, then I would advise suggesting to the anaesthetist that carbon dioxide be measured prior to surgery to establish baseline levels. Hope this helps and keep up the good work.

Cheers, Ian

It is always nice to receive positive feedback from our members. Following her raffle prize win at our last Seminar, Robin Ruys sent this letter to Committee Member Alice Smart.

Dear Alice

I have so much appreciated the lovely large warm textured blanket which you so kindly donated to the PNSW Seminar day. As one who does a little craft work I was amazed that the rug seemed to be knitted in one piece. That was an amazing thought.

Whenever I attend PNSW events I am humbled by the efforts of others. But there is also a sense of relaxation – others have their struggles, many of them heroic, and nobody is in competition as so often is the feeling when attending some other types of organizations such as the musical ones I am involved in.

You have contributed much to the Network over many years and I salute you and others who make it possible for people like myself, still involved in working life, to experience the benefits of belonging to the Network.

All good wishes and thanks

Robin Ruys



2014 Polio NSW Seminar Program

Thursday 8 to Sunday 11 May 2014	St Joseph's Baulkham Hills Centre for Reflective Living	Polio NSW will host the 2014 Polio Health and Wellness Retreat
2014 Seminars	WATCH THIS SPACE IN UPCOMING ISSUES OF NETWORK NEWS FOR SEMINAR NEWS AND FOR DETAILS OF OUR 25TH ANNIVERSARY CELEBRATIONS	

Management Committee - Executive Members Contact Details

Gillian Thomas	President	president@polionsw.org.au	02 9663 2402
Susan Ellis	Vice-President	vicepres@polionsw.org.au	02 9487 3094
Merle Thompson	Secretary	secretary@polionsw.org.au	02 4758 6637
Alan Cameron	Treasurer	treasurer@polionsw.org.au	0407 404 641
Committee Members (for contact details please ring or email the Network Office): Charles Anderson, Anne Buchanan, Nola Buck, Barbara Fuller, Gary Fuller, Alice Smart and John Tierney			

PPN Office and Other Contact Details

Office staff: George, Carlie and Fatma		office@polionsw.org.au	02 9890 0946
Volunteers: Nola, John			02 9890 0953
Susan Ellis	Seminar Co-ordinator	seminar@polionsw.org.au	02 9487 3094
Alan Cameron	Website Webmaster	webmaster@polionsw.org.au	0407 404 641
Mary Westbrook	Q's about polio & PPS	askmary@polionsw.org.au	02 9890 0946
Nola Buck/Susan Ellis	Co-editors Network News	editor@polionsw.org.au	02 9890 0946

Have You Included Your Polio Details on the Australian Polio Register?

The Australian Polio Register was established by Polio Australia in October 2010 to gather information on the numbers of polio survivors living in Australia today, whether or not they contracted polio in this country. There are currently more than 2,000 polio survivors on the Register and this number increases daily. To make the Register truly reflective of the unmet need for polio services throughout Australia, all State polio networks are urging every Australian polio survivor to join the Register which is available on Polio Australia's website at <www.polioaustralia.org.au>. The Australian Polio Register form can either be completed online or downloaded (by you, or a friend with internet access) for completion and subsequent return to Polio Australia.