

POST - POLIO NETWORK (NSW) INC.

NETWORK NEWS

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President's Corner

Gillian Thomas

Welcome to new members and regular readers. I think that at 44 pages this is the largest issue of *Network News* I have produced in my 20 years as Editor! Not that I initially intended it to be so, but there is a lot to tell you about at the moment so I hope you enjoy reading the various articles and reports.

Time is fast approaching for our biennial **Country Conference** which will be held in **Wagga Wagga** on **Saturday, 26 September 2009**, ably hosted by the local Support Group headed by Isabel Thompson. Neil von Schill and the organising committee have assembled a wonderful line-up of speakers. **Full details** of the day and the presentations can be found on **pages 2 to 4**. A **Registration Form** is included with this *Network News* – please be sure to **register by Friday, 18 September 2009**. Everyone is welcome so we look forward to catching up with members from far and wide.

We were delighted with the attendance at our first new-format **Metropolitan Seminar** held on **18 May**. More than 70 people heard from three excellent speakers on diverse topics. We are grateful to Committee members Rachelle and Mandy for their **summaries of the presentations** (see **pages 6 to 11**) written for the benefit of members unable to attend.

Thank you to the many members who have already renewed their 2009/2010 membership. If your address sheet still reads "Renewal Due on 1 July 2009" (or an even earlier year), we have not yet received your membership renewal. We would appreciate it if you could return your Renewal Form and membership subscription as soon as possible. The Network is self-funded and needs your continued support to enable us to provide services to polio survivors and their families.

Remember that if you choose to pay your subscription via **internet banking** you must **ensure that your name is recorded on the internet payment and also email us to confirm the payment transaction and membership details: <ppntreas@post-polionetwork.org.au>**. Without this information it may be impossible for us to credit the payment to your membership. Also, **if you post in your payment**, please be sure to **return the entire Renewal Form** with your subscription.

As Neil also recorded in his Polio Australia report on page 24, we have just learned that we have secured a donation of \$10,000 from a philanthropic foundation, *The Marian & EH Flack Trust*, which will contribute towards running a Wellness Retreat early next year. Our application summary read:

Funding is sought to conduct a three-day residential Wellness Retreat to educate polio survivors and their family/carers in self-management techniques aimed at stabilising and/or reducing symptoms of the late effects of polio (LEOP). The knowledge gained will not only assist people to better manage their condition but can also be shared with the participants' health service providers, facilitating improved care for patients presenting with LEOP. Many GPs and allied health professionals are unfamiliar with the pathophysiology of LEOP which has resulted in ineffective treatment/management and further damage, at great expense to both those involved and the health system. Information and strategies will be provided about stress factors, nutrition, weight management, options for aids and equipment, and home modifications, thereby enabling people to achieve general wellbeing and ensure that they remain as mobile and independent as possible in their own homes.

We are very grateful to have been given the opportunity to conduct a Retreat as overseas experience has shown them to be of much benefit. There will be more on this exciting initiative in the next issue of *Network News*. In the meantime, we hope to see you in Wagga Wagga on 26 September.

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Country Conference - Wagga Wagga

Date: Saturday, 26 September 2009

Time: 9:00 am – 3:30 pm

Venue: Country Comfort Motel
Cnr Morgan and Tarcutta Streets
Wagga Wagga

Refreshments: Morning tea and a light lunch will be provided
The cost will be subsidised by the Network

Cost: \$15 per person – ***please RSVP by Friday, 18 September 2009***

Program:

9:00 – 9:45	<i>REGISTRATION AND TEA/COFFEE</i>	
9:45 – 10:00	Welcome and Opening Remarks	John Winterbottom Wagga Wagga Support Group
10:00 – 11:00	A Model Polio Clinic	Simon Mathieson Polio Services Victoria
11:00 – 11:30	<i>MORNING TEA</i>	
11:30 – 12:15	Managing the Late Effects of Polio and Review of Local Services	Dr Louis Baggio Rehabilitation Physician
12:15 – 1:00	IDEAS NSW Services	Sue Gorman IDEAS
1:00 – 1:45	<i>LUNCH</i>	
1:45 – 2:00	Wheelies with Wings	Brian Wilson Convenor ACT Support Group
2:00 – 3:30	<i>Living with Polio in the 21st Century</i> Overview – Retreat and Conference	Mary-ann Liethof Polio Network Victoria
3:30	Announcements and Close	

*Further details of the speakers and topics they will cover are given on pages 3 and 4
Each session will be interactive and include ample time for questions*

To secure your place at this Conference, please complete the enclosed Registration Form and return it with your payment to the Network's Office by 18 September 2009.

We look forward to seeing everyone there. If this will be the first Country Conference you have attended, please be sure to introduce yourself to a Committee member.

Simon Mathieson – A Model Polio Clinic

Simon Mathieson has recently taken over from Jane Henderson as the Coordinator and Physiotherapist of Polio Services Victoria (PSV) at St Vincent's Hospital in Melbourne. Simon came to PSV from Caulfield Hospital where he had been working since 2003 as a physiotherapist in a mixed hydrotherapy, inpatient and outpatient rehabilitation role. As a Senior Clinician Physiotherapist in Neurological Rehabilitation, Simon has had experience in the rehabilitation of clients following polio, stroke, brain injury and other neurological disorders. Currently completing a Master of Public Health he has a strong interest in optimising the outcomes of rehabilitation in clients following neurological events.

The PSV Clinics in Victoria provide initial specialised assessment and care planning, and offer long term review of people who have had polio. However, Simon's talk isn't directed at making us envious of this service which, being south of the border, is not accessible to us in NSW. As Victoria is the only state that has clinics offering services specifically to polio clients, the aim of Simon's presentation is make us aware of the kind of help available through PSV. Simon will also cover the types of services that a "model" Polio Clinic should offer which will prove invaluable to us as we continue to pursue the establishment of such Clinics in NSW.

Dr Louis Baggio – Managing the Late Effects of Polio

Rehabilitation Physician Dr Louis Baggio manages the Inpatient Unit and Ambulatory Rehabilitation Services at Wagga Wagga Base Hospital, which is part of the Greater Southern Area Health Service in NSW.

The Greater Southern Area Health Service covers 166,000 sq km and has a population of approximately 468,000 persons. There are six main areas of population density at Albury, Deniliquin, Goulburn, Griffith, Queanbeyan and Wagga Wagga and the Area has many smaller rural towns – in all, the Service covers 39 Local Government Areas.

Dr Baggio's presentation will not only focus on management of the late effects of polio but he will be providing information about local support services that can be accessed by polio survivors and their families.

Brian Wilson – Wheelies with Wings



Brian Wilson is a Network member and long-time Convenor of the ACT Support Group.

In April 2009 he travelled to Temora in NSW to learn how to become a "wheelie with wings".

In his presentation Brian will describe his flying training and enthral us with an account of his adventures in the sky.

Wheelies with Wings is a charity and a non profit organisation. Its purpose is to offer to physically disabled people the opportunity to gain a flying experience. WwW awards scholarships for limited flying training, based on a competitive selection process. Aviation has been chosen because of the discipline required and for the independence and freedom it can give.

The scholarships are named in recognition of the courage, skill and determination of Suzi Duncan, a woman who faced the consequences of childhood polio and became a flying instructor. She initiated the concept of WwW, has invented a hand control to make it possible for people with lower limb disability to fly, and has personally raised significant funds to finance the program.

Sue Gorman - IDEAS NSW Services



This session will be presented by Sue Gorman,
IDEAS Community & Advocacy Liaison Officer

IDEAS provides a range of high-quality accessible and relevant information services and products for people with disability and people with age-related disability, their families, carers and other supporters.

As a clearinghouse on disability, IDEAS captures information with specialist expertise, experience, community and/or industry knowledge and contacts and then filters, interprets and disseminates it on request, through a variety of methods. They also provide “soft” information that is not specifically about a service but can assist people with disability to make informed choices about their daily living. IDEAS is widely recognised in New South Wales as the leading information provider in the field.

Services that IDEAS provide include a toll-free telephone information service, an on-line information clearinghouse, a newsletter, high-quality directories of services and products, and an online directory of accessible businesses and services. Sue will tell us all about these services and more.



Mary-ann Liethof - Living with Polio in the 21st Century



The presentation by Mary-ann Liethof from Polio Network Victoria will be a summary of the week long Post-Polio Wellness Retreat and Conference that she attended in Warm Springs, Georgia, USA, in April this year.

This was Post-Polio Health International's 10th International Conference and attracted more than 430 polio survivors, family members and health professionals from 11 countries.

Mary-ann will not only be sharing her own experience of the activities and information presented during those seven days, but also the insights she gained through her travelling companions: Victorian polio survivors Fran Henke, Shirley Glance and Liz Telford.

Where the three-day Wellness Retreat covered aspects of “Body, Mind & Spirit” in a more intimate setting with a group of 64 people, the following three-day Conference program had a diverse range of topics including Post-Polio Examination, Research, Anaesthesia Update, Bracing, and Finding Causes of and Managing Pain and Fatigue, presented by some of the best polio-knowledgeable health professionals in the USA and Europe.

You may think that you've heard it all before, but there's always something new to learn about managing the late effects of polio. This might just be the presentation for you.

The Polio Crusaders:

Disability Activism at Warm Springs in the 1930s

Naomi Rogers, PhD <Naomi.rogers@yale.edu>

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The following article is the abstract of a paper presented at Post-Polio Health International's 10th International Conference held at Warm Springs, Georgia, USA, in April 2009. The abstract is reproduced here with the kind permission of Post-Polio Health International.

During the 1930s, disabled adults at Warm Springs initiated a public disability rights campaign. So effective was this campaign that President Franklin Roosevelt's able-bodied advisors considered it a political threat, and sought to displace the articulate adult polio survivor in the public mind with the image of the poster child, vulnerable, silent and grateful. At the core of this disability rights movement were polio patients who wanted more than a healing refuge. They saw the Warm Springs' high profile as a potent weapon in a cultural war to challenge discrimination against the disabled. Their eight-page newsletter, the *Polio Chronicle*, its slogan "Every Patient a Polio Crusader", boldly protested the narrow, medicalized definition of rehabilitation and provocatively suggested "rehabilitating" prejudiced, able-bodied employers and health professionals. And they consciously redesigned Warm Springs to function as an exemplar of the way polio survivors and other disabled people deserved to live. To make what seemed like a special interest demand into a public right, these Polio Crusaders built a feisty and hedonist community filled with poker games, vaudeville shows and romance.

The community of activists at Warm Springs was part of a broader, nascent disability rights movement. In 1935 the League of the Physically Handicapped protested discriminatory government policies and marched with signs that read "We Don't Want Tin Cups We Want Jobs" mocking the piteous images of the disabled typically promoted by charities and New Deal agencies. But the class allegiances of most Warm Springs patients were worlds away from the League, an organization never discussed in the *Polio Chronicle*. In the 1930s this community was made up of wealthy adults, and from the beginning Warm Springs patients, administrators and medical staff were all white, with, as was typical of other Southern institutions, African Americans working as maids, waiters, body servants, gardeners and janitors.

By the end of the 1930s, with the founding of the March of Dimes, the *Polio Chronicle* had ceased publication, the League for the Physically Handicapped had dissolved, and disabled activism was in retreat. The March of Dimes developed no policies for employing the disabled or battling discrimination. Despite increasing numbers of adolescents and adults disabled by polio, March of Dimes publicity campaigns remade the polio survivor into a hopeful, young child, attractive and eager to walk again, silent and smiling. Now, rehabilitation meant an adjustment to physical limitations and not integration into society, a striving for normality and not an open realism about physical difference. Children were good for fund-raising, but they also signaled the shift back to the treatment of the disabled as the objects of sentimental publicity, and a renewed disregard for the disabled as agents of policy and change. Polio survivors continued to fight social and economic discrimination at their homes, schools and workplaces. The emergence of the Independent Living Movement in the 1960s was spearheaded by a new generation of adult polio survivors, who were children just as Warm Springs oriented its rehabilitative efforts around child patients. Perhaps the legacy of activism can be traced to the inspiring example of Warm Springs as a "Polio's Paradise".

Report on One-Day Seminar – 18 May 2009

Thanks to Committee Member Dr Rachelle Andgel who provided this overview of the presentations at our first new-format Seminar held at the Northcott Centre in Parramatta.

As advertised, this Seminar had something for everyone – covering three diverse areas and speakers. The Seminar attracted over 70 attendees – a great turnout which vindicates the Committee's decision to change the format of our regular information program.

I have concentrated this report on the first two presenters and left the full reporting of Nicola Clayton's succinct discussion of dysphagia causes and management to her fellow Speech Pathologist, Mandy Stubbs. (I have to admit I wasn't aware that Speech Pathologists are involved in diagnostic testing for dysphagia – and suspect referrals to speech pathologists will go ballistic if this gets out!)

All three topics were enthusiastically received by Network members and friends with Darren, Ron, Diane and Nicola each being presented with a thank you gift on behalf of a grateful audience.

Darren Pereira – Stance Control: Ron Bell's Orthotic Journey



Darren is a specialist in complex lower limb orthotics and has a wealth of experience in the provision of Ground Reaction Ankle Foot Orthoses (GRAFO), Knee Ankle Foot Orthoses (KAFO) and Stance Control Knee Ankle Foot Orthoses (SCKAFO). As a member of the Polio Services Victoria team from 1998 to 2009 he has provided consultancy to over 1,300 polio clients.

Since the Seminar, Darren has left Polio Services Victoria to focus on his role as Manager of the Prosthetics and Orthotics Department at Melbourne's St Vincent's Hospital. Darren also has a private practice in Melbourne, NeuroMuscular Orthotics, based in Mt Waverley, and he consults in Sydney on a monthly basis.

The first speaker was Darren Pereira, who has been involved with Polio Services Victoria for over 11 years.

Darren has been teaming with Ron Bell to demonstrate the SCKAFO (Stance Control Knee Ankle Foot Orthosis). Ron has been keen to demonstrate to post-polio groups as a way of acknowledging the assistance he received to fund his orthosis.

Stance control orthoses were released 20 years ago, and are used for post-polio, multiple sclerosis and late-onset muscular dystrophy. They provide knee flexion stability in stance while allowing knee flexion (the orthosis unlocks) during swing

There are 3 main types of stance control orthoses:

- Weight activated – knee joint locks when the client bears weight – this type is generally best for post-polio clients.
- Motion activated – ankle motion causes the knee to lock.
- Load response – stays locked at all times but allows a variable range.

Darren is Australia's expert for orthoses, which have advanced significantly with new technology. The SCKAFO, as used by Ron Bell, is like an external bionic leg. Watching Ron stand unaided for half an hour (which I can't do!) was impressive. When he removed the orthosis and attempted to stand and walk (explaining it was definitely against Darren's advice) it was scary. He couldn't stand let alone walk a step. The entire audience gasped in horror then relief when he reached the chair a metre away.

I had already had a consultation with Darren, and he had lent me the DVD of Ron showing him walking before and after the SCKAFO, but the reality was so much more dramatic.

Ron explained that it wasn't all magic. The orthosis requires retraining in walking and weight distribution to allow the knee to lock and unlock. The process is long and requires significant dedication. It is also expensive. In Victoria some of the cost (up to \$2,200) is covered by Polio Services Victoria, but around \$7,000 extra is still required. Ron was fortunate to have close ties with his local Lions Club who paid the entire cost for him. As he notes, however, it is a lot of money to invest in something which may not be successful for every individual.



Ron Bell demonstrating his weight-activated stance control KAFO to polio survivors in Wangaratta
Photos courtesy of Mary-ann Liethof, Polio Network Victoria

For some time Darren has been consulting monthly in North Parramatta. He has now commenced practice with the physiotherapists at Advance Rehab Centre (ARC) at St Leonards. I had already traced Melissa McConaghy, the founder and director of this purpose-built rehabilitation gym and hydrotherapy centre, and commenced hydrotherapy. ARC has a comprehensive website <www.archhealth.com.au> and can be contacted on 02 9906 7777 for information about Clinic times where you can consult Darren and the physiotherapists.

So, we're closer to my goal for a Post-Polio Clinic – all that's needed now is the funding and Rehabilitation Specialist as the basis for the necessary multi-disciplinary team.

Diane Bull – Stress: the Good, the Bad, and the Not So Cute



Diane Bull holds a Bachelor of Science (Honours – First Class) and a Doctorate of Philosophy, Faculty of Medicine. She is a registered Psychologist and a Director of the forethought consultancy group which deals with all aspects of psychology.

For the past thirty years Diane has held positions at the University of Newcastle, including Deputy Dean and Senior Lecturer and Postgraduate Supervisor in Psychology in the areas of Health, Psychoneuro-immunology, Clinical and Experimental Methodology. Her research over the last thirty years has progressed from laboratory-based research to an applied field of investigating the parameters of immune responses and other factors of wellbeing under conditions of both physiological and psychological stress.

Diane's presentation posed the question "*Does stress interrupt immune function?*".

Numerous studies have documented the adverse effects of stress on various aspects of immune function, both in humans and in laboratory animals. But when people such as polio survivors are under prolonged physiological stress, they are constantly in a state of heightened autonomic activation and may have a reduced immune response for an extended period.

Among other things, repeated stress can result in general wear and tear on an organism, or combine with pre-existing weakness, or new exposure to a virus etc, to produce specific illness which in itself is stressful and maintains the cycle.

Stress can be defined as the external or environmental factors to which people are exposed and the behavioural or biological response to it.

In response to stressors the adrenal glands produce glucocorticoids (steroid hormones including cortisol and corticosterone) and adrenaline (epinephrine to Americans) and noradrenaline (norepinephrine).

This was adaptive for acute stressors, but maladaptive in modern life where stressors are recurrent or prolonged.

In 1956 Selye described the stress response as the General Adaptation Syndrome. This Syndrome describes how prolonged, uncontrollable physical and/or psychological distress may ultimately result in a state of exhaustion. The impact of stress is, however, moderated by the personality and coping capacity.

The 3 stages are:

- Alarm: a high arousal reaction occurs when the organism recognises a threat.
- Resistance: where physiological changes stabilise and arousal tapers as the organism becomes accustomed to the threat.
- Exhaustion: the body's resources become depleted, resulting in disorders of adaptation.

The nervous and endocrine systems work together to maintain homeostasis – normal functioning of bodily processes – and restore stability when there is departure from the tolerance range.

Stress-related diseases occur when physiological systems designed to deal with acute stress are activated for a prolonged period – these diseases include heart disease, diabetes, stroke, cancer, leukaemia and recurrent infections.

Both physical and psychological stressors affect immune response.

B cells and T cells have receptors for glucocorticoids and noradrenaline, and are suppressed with chronic stress. Glucocorticoids also reduce protein synthesis, including antibody formation.

Coping with stress – This is defined as “*The ongoing process of managing demands (internal and external) and/or marshalling personal resources so that demand does not exceed resource*”. There are two main styles of coping with stress such as may result from dealing with chronic health issues: problem-focused coping and emotion-focused coping.

Problem-focussed coping will see you work to reduce the demand, increase your resources, take direct action, seek advice, seek training/instruction, and/or seek assistance/support.

Emotion-focussed coping aims to regulate the emotional consequences and may lead you to denial, avoidance, drug use, and/or illness behaviour.

Diane described physical strategies to help deal with stress: these include diet, sleep and exercise.

Regarding diet she advised that lack of protein can seriously compromise immune functioning. She recommends smaller and more regular meals rather than one or two large meals per day because this leads to better absorption of minerals, trace elements, proteins, and so on.

With respect to sleep, try to adjust your sleeping patterns: in similarity to your food intake, smaller episodes, more often, is better. Ensure a well-ventilated area – over-heating does not allow a good sleep pattern and is detrimental to immune functioning. A darker environment helps melatonin release which aids sleep. Ensure a quiet area – this sometimes means shifting to a different room.

With exercise, maintain a reasonable and appropriate level of activity which could include walking, gardening, swimming etc. Even if you are sedentary, you can try rotating your limbs and doing light stretching exercises. Diane cautioned that excessive exercise is suppressive to the immune system.

Psychological strategies can include seeking help or information that promotes self-regulation of, for example, practical problems, emotional distress, etc. Seek training to learn lifestyle coping strategies, for example, relaxation techniques, stress management, pain management, positive focus, etc. Maintain or create therapeutic support from individuals, groups, family. Maintain social activities, for example, personal growth such as learning a new skill or continuing with your education, or social contribution such as active involvement in institutions, church, political arenas. Particularly important is the ability to be flexible in cognitive ability. Things and situations change, some for the better, some for worse.

I found my way to the PPN Committee in my attempt to channel my frustration with the lack of knowledge, interest and services for PPS into something more productive.

Using the problem-focused coping model Diane outlined above, my mission is to establish a PPS clinic in NSW.

Dysphagia - Practical Management Strategies



Nicola Clayton, Senior Speech Pathologist at Concord Repatriation General Hospital, has been specialising in dysphagia management for over 10 years and was therefore the perfect choice to present to members on this topic at our May Seminar. We are grateful to Committee Member Mandy Stubbs, a fellow speech pathologist, for this detailed report on Nicola's presentation.

Nicola is also the NSW Dysphagia Interest Group Coordinator, has her Master of Science in Medicine (research based Masters examining dysphagia in respiratory disease), has coordinated the Modified Barium Swallow Clinic at Concord Hospital for many years (in which she has seen several post-polio clients) and now supervises the clinician who runs this Clinic. In addition, she is a guest lecturer at Macquarie University, teaching Speech Pathology students about the assessment and treatment of dysphagia in a number of populations including respiratory disease.

Nicola Clayton, the Senior Speech Pathologist at Concord Repatriation General Hospital in Sydney gave an interesting and informative talk on dysphagia ('faulty swallowing') and how to manage this condition.

She began by giving a definition of swallowing which is the process by which food or fluid is taken in and sent from the mouth to the stomach. A normal swallow begins with the Oral Preparatory phase which involves seeing the food or fluid, thinking about swallowing and getting the food or fluid into the mouth. The Oral phase follows and is about taking the food into the mouth, chewing and forming a bolus and getting the bolus to the back of the mouth. The next phase of a normal swallow is the Pharyngeal phase where the airway is sealed off, the swallow is initiated and the bolus is sent through the pharynx (top of the throat) by muscular contraction. The upper sphincter muscle in the oesophagus (food pipe) then relaxes, so the food can pass into the oesophagus. Then the lower oesophageal sphincter relaxes to allow the bolus into the stomach.

Nicola then showed some fascinating films of barium swallows where people could be seen in x-ray swallowing some liquid barium. It was amazing to see what most of us take for granted happening in such intimate detail, in people with a normal swallow.

The respiratory system was then explained, with the trachea (windpipe) leading into the lungs. These have a huge surface area contained in the myriad of tiny bronchioles and alveoli, to soak up all that oxygen.

When swallowing, the airway defence mechanisms come into place. Initially there is the closure of the epiglottis, which flaps down over the trachea to prevent anything entering the windpipe. The vocal cords also close over the airway. Respiration and swallowing are co-ordinated, so you don't breathe in at the same time as swallowing. If the food does go down the wrong way, there is the cough to protect you, mucocilliary action, where the little hairs try to waft the foreign matter out and, as a last resort, cellular mechanisms to get rid of the material and bacteria in the lungs.

If anything goes wrong with any stage of the swallow, this is called dysphagia. This can happen in the general population, due to ageing, disease or injury, and is a bit more common in polio survivors, due to muscle weakness, but not that prevalent. If severe or

chronic, it can lead to chest infections like pneumonia, weight loss, reduced quality of life, reduced appetite and choking. When dysphagia does occur in polio people it can be due to progressive wasting of the mouth and throat muscles; general muscle weakness; reduced breathing/swallowing co-ordination; poor posture; poor cough; and/or fatigue. The incidence (how many people experience it) is highly variable and does not appear to be related to whether bulbar signs were evident at the time of acute polio. If dysphagia does start, it can be progressive, though progression is usually slow.

Dysphagia can happen as part of Post-Polio Syndrome and can occur because there is food/fluid getting stuck in the throat; there is less upward movement of the hyoid (voice box) during swallowing; there is an asymmetrical (one-sided) swallow, due to posture change or weakness; or there may be fatigue during meals. The risks of aspiration (food/fluid going into the lungs) are increased, but the risk is still low for Post-Polio people.

In Post-Polio Syndrome, swallowing can be compromised because of reduced cough strength due to poor posture, reduced muscle strength or fatigue, or reduced strength of exhalation (breathing out) after swallowing. Reduced airway protection and poor mobility can increase the risk of developing a chest infection – especially if aspiration is happening. Some examples of dysphagia are aspiration and also pharyngeal residue (food/fluid getting stuck before going down).

Nicola then showed us some more film of somebody swallowing with aspiration, and with pharyngeal residue. The sight of the fluid trickling down into the trachea (windpipe), as well as into the oesophagus, where it should all go, was quite disconcerting. As was the sandwich stuck in the throat and refusing to go down after many swallows.

So what can you do about dysphagia? Firstly, look out for the signs and symptoms which would be coughing whilst eating and drinking. Secondly, numerous chest infections could be a sign, as could getting food stuck in your throat. Difficulty chewing could be an indication – if not due to not wearing your false teeth! Taking longer to eat meals could be a sign, if not due to problems with your hands, or due to fatigue. Avoiding foods or fluids that are thin, or difficult, like water or lumpy soup could be a sign, as could weight loss. If you suspect dysphagia, seek advice from a Speech Pathologist. Ring your local hospital to find somebody suitable, as not all Speech Pathologists work with people with dysphagia specifically, or with adults. You don't necessarily need a referral to see someone, but will do if you need to have an x-ray movie of your swallow taken.

How can you be safe when swallowing? Position yourself as upright as possible when eating and drinking. Take smaller mouthfuls of food/fluid. Alternate food and fluid. Take your time when eating/drinking. Consider having smaller meals, more frequently. Keep your head in the midline (don't tip your head forward or back, but keep it 'central on top of your neck'). Don't use straws as this involves taking in air as well as fluid, which you don't want to do. See your GP regularly to check that your chest is clear.

In summary: Dysphagia can be a problem in Post-Polio Syndrome, though is not common. It can occur if there is progressive muscle weakness, poor posture, reduced breath control, reduced airway protection, fatigue, susceptibility to chest infections. So look out for the warning signs set out above and seek advice from your GP and/or Speech Pathologist if you are experiencing any difficulties with swallowing.

Nicola was inundated with questions at the end of her excellent presentation and it seemed clear that many were interested and better informed about this topic after hearing her speak.

Our Polio Legacy

This issue we present two more stories in the “Our Polio Legacy” series. We hope that by publishing members’ stories in Network News as well as collecting them for posterity we will encourage other members to contribute to the archive. Our stories are a valuable reminder of the effects of polio in an unvaccinated population and deserve to be told and preserved. Stories of any length are fine and can simply be about a memorable polio-related incident or an account of your whole polio experience. Please send your contributions by email to Merle at <stories@post-polionetwork.org.au> or by mail to the Network.

Wendy Davies



In the last issue of *Network News* we published the polio story of Jean Grayson, the much-loved aunt of Network member and fellow polio survivor, Wendy Davies.

In this issue, it is Wendy’s turn as she tells her own story.

About a week after I turned two on New Year’s Day of 1951, I became an adventurer. Milking was over and Dad had mentioned at morning tea that he was going to inspect some new poddy calves. Mum was preoccupied with morning sickness as she completed the housework and Dad hurried to saddle the horse so I didn’t announce my intentions to anyone. Of course I had to see the poddies. As an only child then, calves were my friends.

Dad was completely unaware that I was following him as he rode his horse up the steep, stony track which meandered through bush behind the house to a paddock about a third of a mile away. He whistled and sang heartily as he went. He was really easy to follow, even though my legs were finding the going tough.

Dad was gone when I finally arrived at the poddies. I clearly remember them putting their heads through the barbed wire fence and sucking my fingers. Playing with the Hereford, the broken bally (Hereford cross) and the little Devon calf was certainly worth the effort of the daunting climb up the hills.

It was time to wander home. Dad wasn’t there as a guide so I tried a direct course through some scrub and round some large boulders. However, I was soon very tired, too exhausted to continue.

Mum and Dad were frantic. They'd searched the property, round the dairy, the pig sties and down the hills to the Condamine River, to no avail. Just when they'd made the decision to call in neighbours and the police, they heard a whimper. There I was, sitting on a large stone, within cooee of the house.

A fortnight later, I was paralysed with polio. The first signs of the virus were a raised temperature and irritability. At the Killarney Show, I'd cried and cried, thrashing my legs around wildly. Neither Mum nor Dad could console me.

Mum packed my bunny rug, Dolly and a stuffed rabbit while Dr Hall, the Killarney doctor, arranged for me to be sent to the isolation ward of Warwick Base Hospital. There I was placed in an iron lung for a week before being transferred to Brisbane Children's Hospital as my condition was serious. When the ambulance men were preparing me for the long journey, Mum's oldest brother's wife, Aunty Jean Grayson, who was a patient in the isolation room next door, told them, "*That little girl hasn't had any breakfast yet.*" They assured her that I would be fed.

I have no conscious memories of my hospitalisation which lasted for approximately six to eight weeks. Mum and Dad were not allowed to visit. Dad's Aunty Lulla, who was a nursing sister in the hospital, advised that it was too upsetting for children to be separated, reunited and then separated again from their families. They fretted and staff could not deal with the ensuing mayhem when the hospital was completely overwhelmed by a never ending stream of new patients.

Nevertheless, there were people on the ward who could comfort me in my distress and ensure that I was fed. These were the beautiful Nurse Anna Petersen from Killarney, the mother of our neighbour, Clare Brosnan, and of course, the ever efficient Aunty Lulla who was nursing somewhere nearby. But it was an Aboriginal boy, Giggy, a fellow patient who was my constant companion and comforter. He was about six or seven.

Ten years later at the end of my treatment for scoliosis, when Mum and I encountered Giggy at the General Hospital in Brisbane (now the Royal), he was the lift driver. It was the only time I ever saw my mother with tears in her eyes. Of course, she did not divulge her thoughts or feelings but I was in no doubt that she was delighted to see him. I felt confused too. When I'd come home from hospital after polio, I'd desperately wanted a black doll like Giggy. This person sitting on a stool was old and wore both callipers and glasses. He was not my Giggy! (Ah, the child's memory and perceptions!)

None of my belongings came home with me. They were destroyed. However, memories of my beloved bunny rug and bunny have endured in unconscious ways. My farmer relatives were appalled to discover that, as an adult living in the city with no poddy calves to feed, I was a licensed backyard rabbit breeder. That was until the entire stock was devastated by the inhumane myxovirus.

On release from the Brisbane Children's Hospital, I commenced treatment with Mrs Hall, the local doctor's wife, who was a physiotherapist. There were lots of local people who went to her for treatment as the polio epidemic had hit the community hard. Bobby Young, who became a Qantas steward, and Jim Kerlin, who still farms in the district, were teenagers. Some, like Aunty Jean Grayson, Betty Hansen, Gwen Pullen and Mary Schute, were married with small children. Other patients came from further afield; Thelma Green who was about six years old was brought by her parents from the Northern Rivers area of New South Wales to attend.

Thelma and I were to meet again when I was first admitted to the adult Ward 3D of the Brisbane General Hospital for treatment for scoliosis at age ten. On the second day, a whole group of youngsters were playing in the solarium when the nurses came with the

trolley to distribute the tablets. I was offered some red tablets but, as I took no medication, refused. The nurses tried every method of persuasion – water, cordial and even my favourite, ice cream, which was a luxury at home. Still I refused. As a nurse was admonishing me, with the clear implication that I was a liar, Thelma waltzed in, picked up her heart tablets and washed them down. Sadly, she died before her sixteenth birthday from her heart condition.

So what do I remember of Mrs Hall's polio treatment based on Sister Kenny's methods? Very little except that Glenn Schulz, another two year old, and I were told to drink lots of olive oil. We also walked to the mantra of "*Heel, toe. Heel, toe.*"

Then there was the bike. It was an enormous tricycle, from a child's perspective, owned by Dr and Mrs Hall's daughter, Dianna. Trouble brewed when Mum discovered that I could ride it unassisted. She, who had overheard Dr Don Watson, my specialist at the Children's Hospital, say "*The little Davies girl will never walk again*" had been dutifully pushing me around the house on the much smaller tricycle presented to me by the Brisbane company, Brown and Broad. Mum reminded me for years that she was not amused to learn that she'd been duped! (I can understand this now as she was in the advanced stages of pregnancy with my sister, Nancy, at the time.)

I have vague memories of having a leg iron built into my left boot initially and of wearing a funny corset thing which took forever to lace up. Neither of these lasted for long. The iron is not in evidence in photographs taken in July, six months after my brush with the virus.

Many years later, Mum and Dad told me of my reactions to them both when I arrived home. For months, I stuck to Mum like a shadow. If she went to the outside toilet, I went to the toilet too and waited on the steps. However, my response to my father was completely different. Far from the two year old who had excitedly followed him up the hazardous path to see the calves, I initially adopted an aloof attitude towards him.

My parents were astounded too, to discover that I could sing the popular song, "*Irene, Goodnight*" in its entirety. Apparently the nurses used it as a pseudo-lullaby! As an adult, I was horrified to discover that not only was it written by a convicted murderer but also that one line of the song threatens suicide by drowning. Some lullaby !!!!

So what has happened over the years? It's hard to put a lifetime of experiences into a few words.

There have been significant struggles. Commencing high school was one of them. Gaining admission to the academic class was problematic because the school didn't recognise listening to ABC Radio book readings as an overwhelming part of my correspondence school core curriculum. (Translate that as I almost failed my Scholarship exam at the end of primary school after more than two years of correspondence lessons.) I will be forever grateful to my parents for insisting that I be given a chance.

It would be easy to skip over the difficulty of becoming part of a very large school community. Being in an adult ward in hospital and living miles from town did not prepare me for entering the world of teenagers in the mid 1960s. I felt isolated and different. My scars (back and both legs) and experiences raised barriers which weren't easy to overcome. Nevertheless, I had friends, achieved a degree of academic success thanks to dedicated teachers and became a prefect. One of my duties in the latter role was street patrol, where we acted to rescue younger girls from doing the washing of visiting musicians in a nearby motel! (The Normie Rowe/Easybeats tour of 1966.)

Winning a scholarship to Teachers' College in Brisbane was not without its problems either. After six weeks, I was informed that as I'd failed the medical, I would be expelled. My orthopaedic specialist, Dr Don Tuffley, ranted and roared about the incompetence and

stupidity of those who made that decision. The Department relented. I taught in Queensland for five years.

Travelling overseas to Europe was the most wonderful eye opening experience. Casual work was diverse and fun. I'll never forget painting bread with melted butter in the canteen of Wrigley's chewing gum factory, sorting Christmas mail, being the pet food specialist in a butcher shop where the elderly customers loved being asked about their Tiddles or Ben, being a tea lady and cleaner at New Zealand House in London, having painted fingernails to cope with cleaning the ashtrays in a pub (Evil Emerald was just the thing for St Patrick's Day too!), and assisting my friend Jan when she operated after hours in the vet practice where she worked. Then there was the Harley Street dentist married to the Arab princess. She'd often be on the loo or in the bath when I came out of the tiny x-ray room! Working for the Jewish dentist at Golders Green was a more sedate experience.

The decision not to teach in the UK was a deliberate one. I needed the freedom to develop more as a person, away from the constant demands of the classroom. I became involved in a number of volunteer groups, working with people with disabilities.

Moving to Sydney in 1979 was another test. I knew only one person – my sister Rhonda's bridesmaid. The waiting list for teaching was prohibitive so I became a receptionist/book-keeper in legal firms. In my spare time, I enrolled in a bushwalking and camping course through Sydney Teachers College, culminating in adventures in abseiling, canoeing and caving. This led me in 1982 to the Associate Diploma in Recreation at Ku-ring-gai College (UTS) where I met my husband, Terry. While I did some field work with the Play Therapist at Royal North Shore Hospital as part of my studies, paid employment as a recreation officer was not forthcoming.

However, our skills did not go to waste. Terry was involved with Bicycle Australia so we volunteered to organise and conduct many three day weekend and longer tours to various locations in country NSW and interstate. This led to the Bicentennial event in 1988 when a small group of international bicyclists travelled with a support vehicle from Cape York to Adelaide via Tasmania.

Eventually, after some unsolicited advice from a most unlikely source, I applied to go back to teaching after an absence of eleven years. Casual teaching eased me into the system. In 1989, I was offered a permanent position, shared between two schools in the Liverpool/Campbelltown area, as a support teacher (learning difficulties). Somehow I found time to study externally for my Bachelor of Education. In 1992, I transferred to Macquarie Fields as a classroom teacher. This was followed by Reading Recovery training in 1995 to work with individual children in Year 1 who were having difficulty in reading and writing. I loved the work which was combined with support teaching.

For eleven years from 1992, Terry and I were also involved as volunteers in a bush regeneration project in Smiths Creek, our local reserve. It demanded study at TAFE as well as regular hands on work. Surprisingly, my political activism on environmental issues gave me a previously unacknowledged sense of strength. I'm amazed at the hidden resources which drove this conservative country girl to challenge authority at all levels of government. How I laugh now when I read some of my passionate, cheeky, thought provoking letters! That's as far as my activism went, however. My one chance to tie myself to a tree in protest at destruction in Smiths Creek Reserve was thwarted by practical considerations. How do protesters go to the toilet when chained up in public view?

During this time, I became aware of the Post-Polio Network, attending seminars and the conference at Kurrajong. While I didn't have PPS, I needed to heed the advice to rest and recover as I often felt exhausted. Looking back, I wonder how I ever had the energy to maintain the frantic lifestyle we led.

It was my mother's death and the loss of Rhonda's family home in the Menai fire five weeks later at the end of 1997 which proved to be a turning point for me. To cut a long story short, health problems arose for which traditional medicine offered no real explanations or more importantly, solutions. I decided to take a year's leave from teaching without pay in 1999 as a fiftieth birthday present. Did I rest? No way! Fascination with colour, through my interest in patchwork quilting, dyeing and photography, led me to a course at the School of Colour and Design at The Rocks. I felt better for the experience and just a wee bit proud of my portfolio!

Going back to school for three days a week at the end of my leave seemed the ideal solution. It wasn't. The Principal knew that over half my spine was fused but for ease of staffing, decided to allocate me to what I considered the most physically taxing position. Relief from face to face teaching was no relief for me. Sadly, for me and the children, I wasn't using my skills teaching literacy at all.

Things weren't going well on another front, either. A night-time incident, involving a teenage girl and two youths in a car, evoked traumatic memories of the many body casts I'd endured during my treatment for scoliosis. *"Be a good girl. Don't cry."* had been the words used to pacify me and ensure my co-operation. Counselling helped me come to terms with my repressed emotions.

When the Department of Education offered its Career Change Scheme at the end of 2000, I jumped at the opportunity. It was a life saving decision to accept the challenge to study for the Graduate Diploma in Expressive Therapies. It was a chance to redress the losses in my pre-teenage years, when I'd been isolated at home, flat on my back in bed for six long months. The course provided a springboard to the wonderful world of art, music and dance. Freedom of expression in the company of new and stimulating friends was just what I needed most of all.

Woodblock printing gave me the chance to "dig out" the painful experiences from the past. Not surprisingly, much of my artwork from that time is related to things which happened in the hospital context and have continued to have an emotional and psychological impact. One of my works was a plaster me, featuring straps of repression and symbolic flaws to represent the burrs in the under singlet, the bruises from the plaster cutters and nicks from the electric saw. Articulating the previously unspeakable things performed in the name of treatment or witnessed in the ward was cathartic. It was not only the visible scars of surgery which needed to be brought out into the open. The emotional scars required sensitive hearing from empathic professionals.

So what am I doing now? Believe it or not, after the intervention of my local Member of Parliament, I'm back teaching as a casual. I have learnt to be kind to myself by choosing my days, how often I work and what schools suit me. Of course, it's stressful. However, to counter that, after school hours I draw with pastels, listen to music and attend an integrated dance class which caters for people with disabilities. While the emphasis is on stretching, there is a healthy component of free form dance which develops my creativity. I don't need a partner either!

Currently, I'm back working with children with learning difficulties three days a week in my old school which has a new executive. It's only for this term. This fits in well with my long term goal of working at Westmead Children's Hospital in their school, preferably as a casual or even as a volunteer. Much depends on my health and stamina.

People have often remarked, *"Oh, you're okay dear. It's just your feet which are the problem."* Orthotics in both shoes and a built up heel are nothing, in polio terms. However, my clothing hides my post polio legacy. It is not just the structural problems in my back and ribcage which create difficulties. When adults have observed the lengthy scar and the

deep hole on my back, some who should know better have commented with obvious distaste, *"Where on earth did you get THAT?"*. It's taken many, many years to accept this aspect of myself but I feel confident that next time I'll be able to say *"Do you have a problem with it?"*.

With children it's a completely different story. With the kids at school, it was easy to joke about being shot, before telling the truth. Sometimes, however, children's thinking processes reveal fascinating ways of jumping to conclusions. A young neighbour did this recently. After his confusion about how our cat, a stray, would be spayed (he thought her genitals would be taken out, leaving a hole), I described how her reproductive organs would be removed. There was a pregnant pause. *"Is that hole in your back from where they took out your organs so you didn't have kids?"* he asked in all seriousness. After the laughter had subsided, our young friend was amazed to learn that some chips of bone had been taken from my shins to fuse my spine. The hole was a result of those operations. While sadly we don't have children of our own, the neighbourhood kids think our place is a pretty good place to play, climb the trees, have a cuppa and eat!

There are other legacies from polio. While some people would see me as determined, I think my contrariness is a direct response to those who said I couldn't or wouldn't achieve anything. Wouldn't walk again? I've learned to walk three times.

"You lazy little devil, you didn't even try" quipped Mum when I failed to master Highland dancing at six. Being a wallflower at the local dances was painful too but deep within me there has always been the desire to move freely to the music. Looking back, I can see *"Strictly Ballroom"* as a relatively recent motivating force. All I needed was a means to achieving that goal. It came through two University of Western Sydney dance graduates, one a friend's daughter who willingly tried to offer a class for "old girls" like me and now, another who had previously taken me to Westmead Children's Hospital in 2001 as a volunteer in an Ausdance program. In integrated dance, there's no need for sequins, fancy hair or stiletto heels. I'm dancing in my street clothes and loving it!

Perhaps the lack of recognition of my success in the academic class at high school has challenged me to reach higher and higher in my studies. Coming thirteenth out of forty-two in the first term back at school after years of correspondence school now seems impressive to me! Not bad for a child who almost failed Scholarship. My next formal educational goal is to complete a Masters Degree some time, some how, in some thing!

I laugh when I think of the vocational guidance man who pronounced gravely "You'll never make a teacher." Funny how I keep going back and becoming a better teacher each time!

Then there's the emotional legacy. Crying wasn't encouraged at home or in the hospital. Now it's so difficult to watch a reunion or parting at the cinema or on TV without the water works starting.

No polio story is complete without reference to helpful means of maintaining or improving health and well being. While I do have a regular GP, over the years Chinese herbs and acupuncture, regular massage and chiropractic, meditation, counselling, Bach flowers, Music Therapy and Feldenkrais have all been of considerable value to me. Music Therapy helped me learn to be spontaneous and innovative, the Chinese herbs taste vile but they work for me, while Feldenkrais has greatly improved my flexibility and gait as I move more easily in the world. I wouldn't be teaching or dancing or participating in fauna and flora surveys without them!

The economic impact of polio cannot be ignored. Medicare does not cover most of my medical needs. Unfortunately, neither does my private health cover. My long wearing, orthotic taking Kumfs are not on the list of recognised providers yet. Teachers Federation

Health is reconsidering their policy. While Kumfs are expensive, buying even more costly surgical shoes from an authorised bootmaker is out of the question. The combined limit of ten visits for massage and individual Feldenkrais is insufficient, too.

At a time when I, like many polio survivors, am unable to continue in the workforce full-time, sustaining quality of life becomes a real issue. This is especially so when the part-time casual income is not supplementary to the family income. At the moment, it is the family income. Access to my limited superannuation is restricted – it is only available at my age if I don't work at all. Maintaining private health cover in the face of decreasing income or support from Centrelink is daunting indeed.

Our lifestyle has always been simple but deciding on priorities has become quite a challenge. A hot water system, new shoes or e-mail connections to the outside world? Yet I'm so fortunate. We own our home, I have a profession which allows me to contribute to and participate in the community and we have some thoughtful, generous friends. The fellowship provided by local Post-Polio Network members is an added bonus.

Goodness knows where life will take me in the future. I know that crises are transient, providing food for thought and the impetus for personal growth. "*Where there's a will, there's a way*" was a family saying which has been firmly embedded in my thinking. As I've discovered, an obstacle is really just an opportunity to be creative. It seems that Expressive Therapies were just what the doctor ordered!



Post script

Wendy wrote her story in 2003. She now writes that she is still doing occasional casual teaching, both in schools and at a Literacy Centre for children with learning difficulties.

Wendy is also now involved with a choir for seniors, *Sweet Tonic*, which was initially a two-year research project into the impact of music on the health and well-being of older people. The group has successfully lobbied for the choir to continue this year.



Pictured: Wendy performing in a Sweet Tonic choir workshop in 2008.

Healthwise, she can still go on bushwalks but suffers from arthritis which appears when it is wet and cold.

Wendy's note concludes "*Have done well!!*"



Bill Bradley



Bill Bradley appears at the front right of this picture taken in 1953 at the Jervis Bay Rehabilitation Centre.

As usual, Bill is surrounded by a bevy of lovely ladies!

What follows is Bill's polio story – but it only covers the early years. Bill has had such a full life there is much more of his story still to come – after all, later this month he only turns a young 73!

Polio, I didn't know what polio was in the early 1950s. I was only interested in sport. My class mate, Betty Cuthbert, and I were thought to be the two fittest kids in the Ermington District. In those days young athletes didn't take vitamins as a replacement as they do today. After playing team sports in Parramatta, I would then run all the way home to Ermington just for practice. Later, it was realised that I was deprived of all resistance for what was to follow.

First term of school was commencing. Off to Eastwood Technical School I went to register, and then back to my old primary school to say good-day. Not feeling too good, I went on home as I thought I had the flu coming on. That night, the so-called flu got worse. Next morning Mum said *"you better stay in bed and I will call the doctor"*. A day off school, that was great. That afternoon Dr Howe arrived and examined me. Not many words were spoken in my presence. That night, I had some tablets stuck down my throat that no doubt the doctor had prescribed. During the night as I was crawling across my bed after going to the toilet my right arm went from under me. Taking no notice I went off to sleep. Next morning Mum came in to see how I was. I said *"my arm won't move"*. Mum grabbed the telephone, and twenty minutes later the doctor was sitting on my bed saying *"you are going to hospital"*. His statement, made no impression. My only thought I had was *"lattice biscuits"*. In the 1950s lattice biscuits were luxuries in our kitchen pantry. Mum sent my brother Noel off to the local shop to buy some. In the mean time the ambulance arrived. My body was becoming limp with weakness, as the ambo's gently placed me on their stretcher bed. They then proceeded to carry me to the ambulance, as a group of locals gathered to enquire what was happening. I was placed in the ambulance by myself. They closed the door and drove off to Prince Henry Hospital, as Noel rode home with biscuits I was to miss out on.

On arrival at Prince Henry I was stripped of all my clothes. My Mum was there to see me stretchered in, but wasn't allowed near me. Our next door neighbour, Ben Swane, used to drive Mum to the hospital each day, whilst I was in isolation. My muscles were rapidly deteriorating. A team of doctors and nurses rolled me on my side and held me there whilst a doctor administered a lumbar puncture. Hovering in back of the room were the physiotherapists with their plaster bandages ready to create plaster casts of my legs. Their ability to cut the tops out of the casts left a lot to be desired. Three hours after the lumbar puncture a doctor was poking tubes up my nostrils to administer oxygen. This was the last thing I remembered before lapsing into unconsciousness.

Days later when I came to and opened my eyes, I discovered, as I thought, I was in a coffin with my head sticking out. The box was as hot as Hades, and I was lying there with just a sheet

covering me. I looked up into the mirror above the coffin and there looking down at me was this beautiful angel, with these lovely shaped boobs. As my condition improved, and being an impressionable fourteen year old, I asked the nurse who sat by my iron lung during the night shift if she could take a photo of the angel. The night shift nurse had a box brownie camera and she took a whole reel of film. I still have a photo of my angel with those lovely shaped boobs. At the 50th reunion of the polio wards of Prince Henry Hospital, she was the only one I could remember by name. Mary Therese Davis, known as Terrie to all.



Bill's angel, Terrie, pictured in 1950

Terrie, who after watching me for days as I lay unconscious, was now sitting all day every day talking and reading to me. It was explained to me during my first conversation with her that I wasn't in a coffin but in an iron lung. The iron lung had a big bellows that pushed air into the box that I was in, which then forced the air out of my lungs. The bellows would then draw the air out and allow the air back into my lungs. Being in the box with air pressing down on your body wasn't so bad. It was the every three hour ritual when they unlocked the end of the box and dragged you out on the tray you were on and plunged a syringe into you. After you had had the needle the nurses would sponge you all over. Then gently they would push the tray you were lying on with your head hanging out of the end, back into the box.

My angel explained to me that life may not be the same when I get out of hospital. She said I wouldn't be playing sport like I had. Now this didn't worry me, all it did was put my imagination into over drive. I was imagining myself with callipers on my legs, and riding a horse bareback across the paddocks. When it came to cricket I thought I could bat and have a mate run between wickets for me. What I couldn't imagine was how I was going to play football. With all my dreaming I never had a thought that my arms might never work. All the discussions with Terrie, and the things I was imagining I would do, certainly passed the time away. When I had visitors, because I was in an infectious room, they had to stay out side the door in the hallway. It never crossed my mind at that time that I could have been one of those six persons who were wheeled out feet first during my isolation period. The only other person down the hallway in an iron lung was Brad Norington, who later became a doctor. After a few weeks they started to leave me out of the iron lung for periods of time so I could breathe by myself. One week later the doctors decided my lungs were strong enough for me remain out permanently. Now that I was out of the iron lung there was no way they were going to get me back into that hot box. The only part of my body I could move was the big toe on my right foot. Being out of the iron lung was a relief to those who thought I wasn't going to live. Little did they know that He wouldn't take me up above, and "Old Nick" said I had too much stirring left in me to be taken below.

Three days later I was moved over to another hospital block. There I was in a huge ward with one other patient, and no angel. They explained that I had to remain calm, as too much excitement might not be good for me. It only took me four days to convince the nursing staff that it would be more peaceful with me in the main male ward. The move was on condition that

I didn't get too excited. How could anyone think that a young teenager like me would get too excited?



On entering the men's B2 ward I met Nurse Paddy Knight who became my replacement angel.

With the move complete, I discovered in the next bed to me was Brad the patient from down the hallway in other block. In our ward was an iron lung. At night Brad would go back into the box to rest. Not me, I was out and I was staying out. Someone with the latest technology had developed a chest fitting iron lung. One morning we were greeted by a delegation of doctors, high ranking nursing officials and those that would be if they could be. The delegation was accompanied by two unknown persons, with two chest machines, looking for two guinea pigs. Brad did oblige to test one, but the machine wasn't a success.

Just after 9 am each day our ward's atmosphere became tense, when a group of females dressed in white came through the doors. They were there to practice torture on us. They were known as physio's. When you are bandaged to a straight jacket for 23 hours a day, without any exercise, you become as stiff as a board. In one hour they would just twist and stretch you. Their intentions were to try to make you as flexible as a rag doll. Brad wasn't a person who enjoyed pain, and I wasn't far behind him. One day I pretended to be asleep all day so I could miss being worked over. That was a mistake, as when they caught up with me it was worse than ever. Brad was also trying ways to avoid being man-handled by the physio. As Brad was being stretched one day, the muscles around one of his knees were torn. All the pain we went through could have been avoided if only the Australian Medical Association (AMA) had been more knowledgeable in the treatment of polio victims. We could have been enjoying being massaged with hot towels, before being placed in the pool. During 1930s and 1940s Sister Elizabeth Kenny was an occasional visitor to Prince Henry Hospital, in an advisory capacity. Her visits were described in "A Coast Chronicle", the history of Prince Henry Hospital, by Dr CR Boughton, Director of Physicians, Infectious Diseases Division, in the 1960s. There are members of the AMA today, who are still not knowledgeable enough in treating post polio patients.

Brad and I, without the knowledge of others, regularly talked about suicide. Brad being of medical mind was able to explain the "hows" and "how nots" about the subject. During our conversations we came to a decision, if we were still on our backs at a set time in life, no doubt being a burden to others, it was decision time. For the both of us, in the long run it was all talk.

At night I would sweet talk the junior nurses into undoing the bandages that were used to tie us into our straight jackets. They would then roll me onto my side and gave me a back rub. Our beds was covered with a mosquito net. The nurses were able to kneel down under the mosquito net and talk until the Night Sister was about to do her rounds. Sister in charge was none the wiser that I slept on my side for the night. Next morning before knock-off time, they rolled me

back and strapped me into my straight jacket. At breakfast time, I became one of the lucky ones. The nurse had to feed me, as with all meals. After eating, the nurse would then push my bed out onto the veranda. It was a mad scramble to get the beds out before Sister Armstrong walked the length of the hospital, from the Nurses' Home. If there was one cloud in the sky, she would have us inside for the day. If we got out, we had to be back in for lunch.

Visiting time was the best hour of the day. You may not have had a visitor, but everyone shared. My school sports master used to bring a car load each weekend to see me. Brian Palmer, my representative football coach, was a regular visitor, as was Nick Shehadie, who later became Sir.

About 10 months had passed, and the wards were filling up with patients. Prince Henry Hospital had 250 polio cases in 1950 and 450 in 1951. November 1950 happened to be the worst month for admissions, between then and March 1951, with up to 40 patients a week. It was decided that I would be transferred to Ryde Hospital.

Ryde was the place for me, when I found out that I was the hospital's first polio case, I was able to stretch the truth with what I was able to do. Staying out of my straight jacket for a few hours a day was the first thing I convinced them to do. I was getting a little more exercise as the nurses were throwing my legs and arms about, also rolling me to and fro. Physio treatment wasn't as bad at Ryde as at Prince Henry. On the day that Dr Scougall was coming, I would rest up in the straight jacket. Some of the nurses used to wonder why I had all my splints on and strapped in. They accepted my answer, "*just resting*". As soon as the doctor had left the hospital, I became un-rested. It was about fifteen months from when I could move my big toe to when I sat up for the first time. Then two months later Dr Scougall said to my parents "*take him home, he's a hopeless case, and bring him back when he's about twenty one, and we will try transplanting muscles*".

My mother read an article in a newspaper about a Mr Featherstone, a quack, who had been run out of Victoria by the Medical Board. This so-called quack had been treating polio cases. Mum tracked him down, and had him treating me regularly with his style of treatment. His style was the same style as Sister Kenny. After a while with his treatment, I was on my feet. Dad put a length of water pipe from our fig tree to a post. As I could use my left hand, I would walk in a fashion along the pipe, and walk crab wise back. I never did count the number of times I went from the post to the fig tree and back. Then the Medical Board caught up with Mr Featherstone, and the Commonwealth Government caught up with me.

The Government sent me down to the Jervis Bay Rehabilitation Centre, to be educated back into the workforce. Going to Jervis Bay Rehab was the greatest thing the Commonwealth Government has ever done for me. Forget about educating us back into the workforce; we were educated back into society! There we were 52 of us, and a minimum of 200 and a maximum of 600 females each week throughout the village of Jervis Bay (*Ed. some of them feature in the group photo at the start of this polio story*). We had a rehab racket going. We knew when they arrived and where they were staying. We had our own weekly newspaper, the "Bay Breeze Brett". Outside the hours of 9 to 5, we had a well organized social calendar. We also had individual conducted night tours for young ladies to see the luminous ducks. These tours could only happen when the Naval fleet was in the bay. The ships were anchored 3 to 4 kilometres from the shore. During the evening, pilot boats travelled back and forth between the ships. On top of the pilot boats was a little clear light. This little light, in the still of the night and darkness, would float across the water and disappear behind a ship, only to reappear later. The little lights on the pilot boats were the so-called luminous ducks. Mornings were spent down at the pool, in the company of others. On our way up to the quarter deck for lunch, a group of girls would be spotted coming around the headland. First part of the plan was to take me out of my wheelchair and sit me on the road. Next they would take Neville Langford's crutches off him, and place them up the road. The girls would arrive, we would introduce ourselves, they would get the crutches and my wheelchair, put me in it, and then push us up to fellows at the top of the hill. What a wonderful year that was at Jervis Bay!

Getting back to the reason I was sent to rehab, I was getting stronger as the weeks went by. I used to walk around like a wound-up doll, hanging on to the back of a fellow who had had his skull smashed during a car racing accident at Parramatta speedway. He dragged me around for months. Then one day he walked me out on to the lawn. He said “*stand there*”, and he walked away. Then he said “*walk*”. I had two options, one I could have fallen A over T or, as I did, I took his advice. End of story.

At the other end of my Prince Henry ward was Doug Sutherland. In 1997 when I joined the Post-Polio Network, Doug announced that he thought I would have died when I went to Ryde.

Nurse Paddy Knight (now Marshall) also thought I may have died when I went to Ryde. Paddy made many enquiries of my whereabouts over the years with no answers. Nobody had heard about me because I hadn't joined the Network until the mid 1990s. Paddy noticed my name on the guest list of the 50-year reunion of Prince Henry Hospital's polio wards. Thinking it might be me, Paddy came from Ballarat to check if it was really me. After 50 years Paddy is now a part of our family.

I am still stirring and have had, and am still enjoying, a very full life.

Low Cost PC for All Centrelink Concession Card Holders

A low cost PC is now within reach of Centrelink customers through a partnership between Centrelink and WorkVentures. Centrelink customers can purchase their own professionally refurbished, internet ready, Pentium 4 PC pack which includes Windows XP Pro, Office XP and free phone technical support from just \$250 plus delivery. The low cost PC offer is available to all Centrelink concession card holders. People interested in purchasing a low cost PC can contact their local Centrelink office, phone WorkVentures on 1800 112 205 or visit the WorkVentures website at <www.workventures.com.au>.

Queen's Birthday 2009 Honours List

In the Queen's Birthday Honours announced on 8 June 2009, we were delighted to see that Glenn Gardner, the immediate past CEO of Northcott Disability Services, had been honoured for his work for the community and in particular with people with a disability by being made a Member of the Order of Australia (AM). Glenn's citation read: “*For service to people with disabilities through executive roles, particularly with the Northcott Society, and to the community.*” Glenn has always been a good friend to polio survivors, both throughout his role at Northcott and more recently as the CEO of Ability First Australia. His honour is richly deserved.

Can You Help to Promote the Network ?

We are most grateful to everyone who has been able to distribute our pamphlets widely throughout their local communities. If any member can help to get the message out about the late effects of polio and the Network by putting more pamphlets on display in, for example, pharmacies, doctors' surgeries or waiting rooms, clinics, shopping centre notice boards, libraries and community health centres, please contact our Office on (02) 9890 0946 or by email at <office@post-polionetwork.org.au>, and some will be posted out to you.

Polio Australia - A National Voice For Polio Survivors

Neil von Schill

There have been some significant developments in the fortunes of Polio Australia since we last reported.

As indicated in our last newsletter, Gillian and Mary-ann devoted a great deal of time and energy in developing a funding submission to the Federal Government addressing "*Education of Consumers in Chronic Disease Self-management and Lifestyle Risk Factor Modification*". Unfortunately our quest for \$200,000 was unsuccessful but we are following up the issue with Federal Politicians. Never daunted, we have since applied for \$30,000 through one of the philanthropic foundations, The Trust Company, for money to employ a part-time Project Officer to begin developing policies and programs for Polio Australia. We are awaiting advice on the outcome of that submission. We are also hoping that a submission made to GlaxoSmithKline (polio vaccine producer) in March for \$15,000 will be successful.

Your Network also applied to *The Marian & EH Flack Trust* for \$20,000 to conduct a Wellness Retreat in NSW, a scaled-down version of our unsuccessful Australia-wide proposal. The Retreat plans to use the services of a range of state-based health professionals to assist polio survivors to better manage their condition with the participants then being well placed to disseminate what they learned to other members. We lodged this application in anticipation that a successful Retreat will serve as a "proof of concept" and facilitate a further proposal for Retreats across Australia as other national funding opportunities become available. As this issue of *Network News* went to press, a donation of \$10,000 resulting from this submission was very gratefully received. Watch out for more on the NSW Retreat, probably to be held during March 2010, in the next *Network News*.

In April of this year, one of our enterprising Central Coast members, Peg Hatherly, wrote to her Federal Labor Member, Jill Hall MP (Member for Shortland) inviting her to a meeting to discuss polio issues. Jill agreed and, early in May, Management Committee member, Diane Bull, Polio Australia Committee member, Neil von Schill, and Jill Hall met at Peg's home. This was a very fruitful meeting with Jill Hall being very supportive of Polio Australia initiatives. The outcome was that she offered to arrange a meeting with the House of Representatives *Standing Committee on Health and Ageing* of which she is a member. We are very grateful to Peg Hatherly for taking the initiative to arrange this meeting with her Federal member.

Thanks to the interest and commitment of Jill Hall, representatives from Polio Australia addressed the Health and Ageing Committee on 24 June 2009. Our delegation comprised President, Gillian Thomas, Committee members Neil von Schill and Mary-ann Liethof, John Tierney of Government Relations Australia, and Peter Garde. Early in the morning we presented our case to the Committee and had a very good hearing. One of the members, Victorian MP Catherine King whose mother had polio, showed great interest. Later in the morning we met with key Opposition members including Liberal members Darren Chester, Greg Hunt (*Shadow Minister for Climate Change*) and Peter Dutton (*Shadow Minister for Health*) and National member Mark Coulton (*Shadow Parliamentary Secretary for Water Resources and Conservation*). We then lunched with Bruce Billson (*Shadow Minister for Sustainable Development*) and Senator Mitch Fifield (*Shadow Parliamentary Secretary for Disabilities, Carers and the Voluntary Sector*). All these members were very supportive of our cause and we are grateful for their encouragement.

By the time we had a debriefing session with Jill Hall late in the afternoon a number of significant developments had emerged. Jill and her Labor colleague Catherine King have agreed to be Parliamentary co-Patrons. From the Coalition ranks, Greg Hunt had earlier

offered to take on a similar role. His colleague from the Nationals, Mark Coulton who we had also met last year, also agreed to be a co-Patron. The value of having a number of parliamentary co-Patrons is that they have pledged their support to assisting Polio Australia to achieve its goals through seeking Federal funding.

In another development, Catherine King had moved, and Jill Hall seconded, a Notice of Motion calling for the recognition of the plight of polio survivors and their needs. A debate resulting from such a Motion is not a foregone conclusion, and many Motions make it no further than the Parliamentary Notice Paper. To our delight, however, Catherine's Motion was debated in the House of Representatives on Monday, 17 August 2009. Please see pages 26 to 31 where both the motion and the speeches of those who supported it (Catherine King, Darren Chester, Jill Hall and Mark Coulton) in the 20 minutes available are reproduced in full.

A return trip to Canberra has been scheduled late in November to build on the support achieved during our August visit. Our special thanks are extended to John Tierney for arranging the meetings with supportive members of Parliament. This groundwork is now providing a wonderful foundation for our further endeavours.

Help Us to Help You – Please Engage Your Local MP !



Polio Australia Inc

The Vision . . .

Polio Australia will standardise quality information and service provision across Australia, ensuring polio survivors have access to appropriate health care and the support required to maintain independence and make informed lifestyle choices.



Polio ... forgotten, but not gone

Polio Australia Inc ♦ PO Box 888, Kensington NSW 1465 ♦ 02 9663 2402

Download the above brief (1.5 MB) from our website
www.post-polionetwork.org.au/brief.pdf

Polio Australia Committee Members are encouraging polio survivors in all states to make your local MPs aware of the issues faced as you cope with the late effects.

So ... if YOU have the ear of, or are willing to approach, your local MP (particularly Federal) ... please try to meet with him/her before we next go to Canberra on 24 November.

Let your MP know what services you require. If you have had polio, tell them your polio story and how the late effects are personally affecting you. If you care for a polio survivor it is just as important that you are heard. Please speak out!

To help you, we have developed a briefing paper (*cover shown at left*) which gives background information about polio and its late effects together with details of Polio Australia's goals and first four-year plan for service development. You can download the brief from our website (*see link at left*), or ring our Office on 02 9890 0946 for copies.

We encourage you to leave a copy of the brief with your MP. Its use will give polio survivors, their families and carers a united voice and ensure a consistent message is given across Australia.

Finally, **please be sure tell us who you have spoken to, and what their response was.** We need to know who will support us in our quest to get funding for Polio Australia so we can keep them up-to-date with our activities on your behalf, and possibly meet with them ourselves in Canberra on 24 November.

Commonwealth of Australia - House of Representatives

Private Members' Business - Monday, 17 August 2009

Polio Survivors

Catherine King, Member for Ballarat, moved the following Motion in the House of Representatives and we were thrilled that three of our Parliamentary co-Patrons were able to take part in the debate. Being in the public domain, extracts from Hansard, such as that below, are able to be freely reproduced (with the proviso that extracts are adequately cited and that they are quoted in context).

That the House recognises that:

- (1) polio survivors continue to be the single largest disability group in Australia today, numbering in the tens of thousands;
- (2) this number not only includes those who contracted polio in Australia during the epidemics last century, but also young polio survivors who have migrated from countries where polio is still prevalent or only recently eradicated;
- (3) the needs of polio survivors have been largely neglected since vaccination against the disease became a reality, and as they age with chronic disabilities this neglect must be addressed as a matter of urgency;
- (4) over the last 20 years much attention has been drawn to the development of new, previously unrecognised, symptoms which occur in people who were thought to have reached a stable level of recovery after the acute disease;
- (5) symptoms of the late effects of polio include unaccustomed fatigue unrelated to activity, decreased strength and endurance, pain in muscles and/or joints, an inability to stay alert, weakness and muscle atrophy, muscle and joint pain, muscle spasms and twitching, respiratory and sleep problems, swallowing and speaking difficulties, depression and anxiety;
- (6) over the last 20 years polio survivors have established state based post polio organisations to provide information and support for fellow survivors, and that these networks are run by polio volunteers who themselves are experiencing increased disability and decreased mobility; and
- (7) in the coming years it is increasingly inevitable that many state networks will cease to function as volunteers find themselves unable to continue the service, thereby creating the necessity for a central body, Polio Australia, to take over responsibility for state functions.



Catherine King

Member for:
Ballarat (Victoria)
Australian Labor Party

7:25 pm I move this motion on polio survivors to bring to the attention of the House the continuing impact that polio has on our community. Many would believe that we have managed to consign polio to the annals of medical history. Through mass immunisation we have managed to almost eradicate polio throughout the world, although there are still cases diagnosed in developing countries as immunisation coverage has been somewhat slower there. Most of us will have seen some of the awful images of children and young teenagers struck down by this disease — again, seeing these as images that are part of our historical past.

During the early to middle 20th century poliomyelitis impacted the lives of thousands of Australians. It is a very old disease where, conversely, as our hygiene standards improved, the immunisation protection passed on by mothers to their infants lessened. It is difficult to put an exact figure on the number affected as many cases did not require hospitalisation and were therefore never recorded, but many resources put the number at over 70,000.

This disease crippled not only individuals but communities in which they lived. This horrific disease terrified Australian communities as it was not known how it was transmitted, with the disease not being brought under control until the late 1950s. It struck down children — over 50 per cent of cases were children under three — and teenagers across the country and, if you look at the Polio Victoria website, there is a roll of Victorian polio survivors. It is heartbreaking to see the ages of those, from six months old to one-year-olds, to seven-year-olds, to those in their teenage years and their early 20s.

For those children and young people who survived, they recovered from polio without any, or only mild, disabilities. They thought they had left polio behind them when they exited from the hospital and treatment facilities. They were all keen to get on with their interrupted lives. They finished school, they worked. Many married and had children and grandchildren. They participated in sport, helped out at school fetes, were active in public life, and contributed alongside other members from their generations to Australia's growth.

But, as this generation has aged, for some of them the effects of that dreadful childhood illness have come back, and I refer to post-polio syndrome, a not widely known syndrome but one that, nevertheless, has come to have a significant impact on the lives of those thousands of polio survivors. We now see new symptoms striking them, with effects such as fatigue, increased pain in muscles and joints, declining strength and endurance, an inability to stay alert, weakness and muscle atrophy, muscle spasms and twitching, respiratory and sleep problems, swallowing and speaking difficulties, and depression and anxiety. It is critical that those suffering from post-polio syndrome receive early assessment and intervention.

Unfortunately, not only do many members of the community lack a sound understanding of post-polio syndrome, but many health professionals are also unaware of the condition. Survivors of post-polio syndrome report that many of them have had difficulty in getting a diagnosis, often having been subjected to many years of testing and at times wrong diagnosis, let alone then trying to get access to support services.

The advent of state based and local polio support groups is assisting, but there is clearly a need for a greater role for national bodies such as Polio Australia to provide advice to the federal government and health professionals for the development of policy and education programs to improve the lives of those impacted by the late effects of polio. Polio survivors continue to be the single largest disability group in Australia today, numbering in the tens of thousands. This disease still haunts those sufferers decades later. Many of us in parliament are aware that former member and former Labor leader Kim Beazley was a polio survivor.

On a personal note, my mum, whose 80th birthday we celebrated on the weekend, contracted polio in 1946 and spent her 17th birthday in Fairfield hospital. She emerged after a year fully recovered, but on developing muscle weakness and a limp in her 50s was diagnosed with post-polio syndrome. I know that it has affected her significantly as she has aged — not something that we as a family have always understood. I think that particularly those like my mum, who experienced such a debilitating illness in their early lives, have been determined to stay well and they certainly have a lot of pride about their being physically strong and capable. Acknowledging and coming to terms with having post-polio syndrome has been really hard for many of them. I encourage those who have members of their families who have had polio to inform themselves about the syndrome and, whilst not all survivors will be affected, I cannot stress enough the importance of an early assessment and access to appropriate services.

I thank those members who are supporting this motion this evening. I know that it does mean a lot to polio survivors to have what is happening to them recognised by this House. I certainly commend Polio Australia and the state based organisations and the local support groups such as the Ballarat Polio Support Group in my own electorate for the work that they are doing to support post-polio syndrome survivors.



Darren Chester

**Member for:
Gippsland (Victoria)
National Party**

7:30 pm In rising to speak on this important motion before the House, I congratulate the member for Ballarat for raising the issue and her personal insights particularly in the context that polio survivors continue to be the largest single disability group in Australia today. Like the previous speaker, I have met with the representatives from Polio Australia and sufferers from within my own electorate and it has given me a better insight into the challenges that many Australians face.

The epidemic of this terrible disease during the last century is certainly well known, but the continuation of suffering by those affected has largely gone unnoticed in our modern society. Indeed, it is fair to say that polio is largely seen as a disease of a previous generation. There is a lack of understanding about the late effects of polio or post-polio syndrome and the impact that the disease is having on all of our communities today.

Within our local communities the effects of the disease continue to haunt many polio survivors and immigrants who contracted the disease before they actually arrived on Australian shores. I do not suggest for a second that our medical professionals have been complacent about their recognition of the disease. I think that we would all agree that there have been several other medical issues that have perhaps attracted more attention in recent years and post-polio syndrome has not been recognised to the extent that it probably needs to be in the future. I believe that perhaps this lack of recognition has taken away the emphasis that the medical system previously had on eradicating polio but also in providing adequate care for people going forward.

It is a case that Polio Australia have made throughout their campaign and their slogan is: "*Polio forgotten, but not gone*". As I said, polio is seen as a disease of a previous generation and there is a concern that many people are actually reluctant to talk about their experience and the effects that the disease has had on them throughout their lives. Unfortunately there remains a certain stigma that surrounds this terrible disease, which we as a society, I believe, have to try to overcome and remove if we are going to provide the assistance required in the future.

I believe that the lack of communication and financial support between the polio support groups and the community has probably contributed to a lack of funding across all levels of government to investigate and resolve many of the effects and the problems associated with post-polio syndrome. Indeed, I am advised by the Parliamentary Secretary for Health that the Department of Health and Ageing does not currently provide any specific funding to support post-polio syndrome. The Department's role under the current health funding arrangements is limited to providing grants to the state and territory governments and they decide their own priorities.

The effects and the problems of post-polio syndrome are continuing to grow as the majority of the polio survivors become older and more reliant on assistance from support groups and carers. Naturally, as our polio sufferers age, their health needs will become more complex. Having met recently with Polio Australia, I understand the need for funding to assist the support groups that work with the sufferers of this disease. I was advised by the group that there are approximately 40,000 people suffering from a paralytic form of the disease and the number of people suffering from the non-paralytic form could be as high as half a million. Importantly, there are forms of the disease that show symptoms similar to other medical ailments, making it even more difficult for the medical profession. This can lead to people with the disease being misdiagnosed or undiagnosed completely and such a failure to diagnose the late effects of polio, or post-polio syndrome, can lead to an inappropriate treatment which, as Polio Australia volunteers informed me, can actually lead to a further exacerbation of the condition and an escalation of the symptoms for those sufferers.

There lies one of the most significant problems for Polio Australia. On a database at the moment

they have about 1,500 people, I understand, who are regarded as being affected by the disease and are registered on their database. They need to expand that and get a better handle on the actual numbers of people involved in that, and that is going to require funding. A significant amount of work is being done on the ground by the support groups to meet the growing demand throughout regional communities, but a concern is that throughout all these support groups there is actually only one paid role in Victoria at the moment. This lack of paid support is an issue for us for a range of medical conditions, but certainly in polio it is emerging as a major concern for Polio Australia.

Polio Australia have argued — and I believe quite rightly so — that without the government's future support they will have a further impact on the volunteers who are required. The burden that is falling upon these volunteers is probably too extreme for them, particularly as many of them are directly affected by the disease themselves. They are right in saying that help is urgently required to help them support sufferers of post-polio syndrome in the future. Too much of the burden is falling on the kind-hearted volunteers in our community.

I believe it is essential that the federal government works with the polio support groups, encourages more volunteers and further assists organisations like Polio Australia in its endeavours. It is important that any services that are provided in the future are made available to people in rural and regional areas, and that we take steps to overcome that tyranny of distance which prevents people from accessing services. I commend the member for Ballarat again for bringing the matter to the House's attention.



Jill Hall

Member for:
Shortland (NSW)
Australian Labor Party

7:35 pm I second the motion moved by the member for Ballarat and, in doing so, I would like to stamp my contribution on this debate by thanking Peg Hatherly from Buff Point who I met with on 8 May this year. It was Peg that brought to my attention the plight of people suffering from post-polio syndrome, or late effects of polio as she likes to refer to it. Present with Peg were Neil von Schill and a local GP, all people that had suffered from polio earlier in their lives and now were experiencing symptoms associated with the late effects of polio.

It was from this meeting that I arranged for them to come and talk to the Standing Committee on Health and Ageing. On that day they were here, they met and spoke with a number of members. It was interesting to learn just how many people had relatives and friends who had actually been affected by polio. My own grandfather suffered from polio and my memories of him are of a little man that always wore callipers.

The issues associated with post-polio syndrome are quite enormous. Peg is a person who has been quite debilitated through her life because of suffering from polio at a younger age. As she has aged, the effects have become much worse and she has become much more debilitated. It took a long time for people to actually recognise what the problem was. By using Peg as an example, it emphasises the problem that sufferers of late effects of polio have.

Whilst polio is now a disease that has been virtually forgotten by our community and health professionals, it is still present but in a very different form. It was in the late 1950s that the immunisation program became widespread throughout Australia, but very few health professionals and even doctors have experience in dealing with people who have suffered from polio at that acute stage. Just recently, as has already been stated in the House, many people that have had polio have developed symptoms later in their lives.

Whilst previously polio, it was considered that once you recover from the acute stage of polio, whatever your residual disability was, that was deemed to be the level of your recovery. What has

subsequently happened is that there has been a slow degenerative process associated with it.

In a previous life, I worked as a rehabilitation counsellor for people with disabilities and that was the first time I had contact with a person who was actually suffering from post-polio syndrome as it was called at that time. The one aspect that was most debilitating for him was the fact that he suffered from really acute depression. That is one of the many symptoms that are associated with post-polio or late effect polio syndrome, along with fatigue, muscle weakness, pain and a general and rapid decline in physical ability.

I think it is time that parliaments and governments of all persuasions acknowledged the fact that more people suffer a disability from polio than from any other disease. We need to assess its impact and ensure that the right education is provided so that people can not only recognise it but also put in place the right sort of support for those suffering from the late effects of polio. Education is a key factor but we should also do everything in our power to look at supporting Polio Australia so that one body has overall responsibility. Once again I commend the member for Ballarat for bringing this important motion to the attention of the House.



Mark Coulton

Member for:

Parkes (NSW)

National Party

***Shadow Parliamentary Secretary for
Water Resources and Conservation***

7:40 pm I would also like to commend the member for Ballarat for bringing this motion on polio survivors before the House and also for relating the experience of her mother. Often the best way of getting a message across in this place is through personal experience, and I thank the member for that.

I am honoured to be here tonight. Recently, I was asked to be a patron of Polio Australia — and I suspect that others in this room have been as well — and so it is a great honour for me to speak on polio tonight. The three previous speakers have probably covered this issue pretty well. However, I think the real issue is that, since the threat of another polio epidemic was put away in the late fifties and early sixties, polio as a disease has been largely neglected. I probably did not realise the significance of lining up with other kids in my class in primary school and being administered the very sweet tasting pink liquid that was presented on a tiny plastic spoon. At the time, it was not significant but I was probably one of the first generations to be largely polio free in Australia.

Polio survivors are one of the largest disability groups in Australia. There are tens of thousands of polio sufferers living in Australia today. This group includes not only Australians but also immigrants from countries where there were no mass immunisation programs for polio. Over the last 20 years, there has been increasing concern about the victims of polio succumbing to unexpected new symptoms 40 or more years after their initial infection. People in their 40s, 50s, 60s and 70s are experiencing what is called 'post-polio syndrome'. The sinister nature of this syndrome is that it is often misdiagnosed and, hence, mistaken for other illnesses. The symptoms include fatigue, decreased strength and endurance, pain and weakness in muscles and joints, respiratory and sleep problems, swallowing and speaking difficulties, depression and anxiety. A whole raft of other illnesses would fit that description.

If post-polio syndrome is not detected early, it can lead to further complications. It is now generally agreed that, in order to minimise the severity of any new symptoms, early assessment and intervention is essential. After a full assessment, post-polio sufferers may be referred to one or all of the following: respiratory specialists, speech therapists, orthotists, physiotherapists, occupational therapists, psychologists or a pain clinic.

One thing that I do not think has been discussed tonight and that is quite dangerous is that a person suffering from post-polio syndrome must avoid using many of the common drugs. These include muscle relaxants, cholesterol reducing medicines, local anaesthetics, general anaesthetics

and painkillers such as aspirin for dysphagia. Polio Australia told us that, if someone is not properly diagnosed and they are being confronted with another illness, their life can be put at risk if these drugs are administered to them.

During the past 20 years numerous state based groups have been formed by polio sufferers. These groups are run by volunteers who suffer from post-polio syndrome themselves and who aim to provide information and support to their fellow sufferers. In the minute I have left I would like to pay tribute to that brave band of Polio Warriors. They march around this place and they knock on doors. They are under-resourced and they are doing it for no other reason than to try and help their fellow man. Quite frankly, they are putting themselves through a great amount of discomfort in doing what they do.

I would also like to pay tribute to the people from Polio Australia. One of the things that I think I can do as a local member — and I have to admit to having trouble with how to word it — I hope without creating mass panic is to highlight in the newspaper that it is an issue that people need to be aware of. I am just struggling with how to do that without having all the doctors' surgeries overrun with everyone believing they have got post-polio syndrome. With the help of Polio Australia I hope to do that.



Infantile Paralysis - How To Forestall It

The following article by an unnamed Paediatrician appeared in the Melbourne newspaper "The Argus" on Saturday, 21 February 1931. It is readily available to us almost eighty years later thanks to the internet. The National Library of Australia, in collaboration the Australian State and Territory libraries, began a program in March 2007 to digitise out-of-copyright newspapers. In July 2008 the Australian Newspapers Beta website <<http://newspapers.nla.gov.au>> was released to the public. This is a free online service that enables full-text searching of newspaper articles. The service includes newspapers published in each state and territory from the 1800s to the mid-1950s, when copyright applies. The first Australian newspaper, published in Sydney in 1803, is included in the service. By 2010 the service will comprise 40 million searchable articles. Predictably, considering the years spanned by the online newspapers, a search for "polio" reveals much of our history.

The prevalence of infantile paralysis renders appropriate a description of the conspicuous symptoms of this terrible scourge of young life, and an outline of measures which may be taken to forestall it. It should no longer be called by the popular name, since the use of human immune serum warrants a new conception of the possibilities of treatment. It is a crippling disease, therefore the great necessity is to prevent the oncoming of the paralytic stage. It is not a disease which kills, as pneumonia does, but it may kill. It spares neither the weak nor the strong. It lays waste indiscriminately. It attacks various muscles or muscle groups and renders them useless, or, at best, gravely impairs their functional power. It is a disease which affects muscles through nerves. Among those affected frequently are children of an age so young that they cannot describe their feelings. It is so at present; the incidence recently has been heavy upon children between the ages of two and five years. The worst effects can be forestalled in many cases by watchfulness. It is a germ disease, but the germ has not been positively identified. The germ is so small that it can pass through the pores of the finest filter. It is communicated by those who are infected or by "carriers". Mothers throughout the State will be able to aid the doctors by noting carefully the symptom-complex which characterises the disease. Early diagnosis is all-important, for upon it depends effectual treatment. This is the administration of immune serum at a stage early enough to prevent muscle paralysis. The disease is notorious for its protean forms. The onset may be announced by an illness extending over one or two weeks. It may appear insidiously as in a little boy who, when playing with his mates upon a lawn, gave in because he could not use his leg.

A Typical Case

The following may be regarded as a typical history of a sporadic case. A mother, living in the country, noticed that her daughter aged four years had been irritable and "off colour" for a few days. Casting her memory back, she realised that the child had not been herself for a fortnight. She had "gone off her food". She had developed within the last week a nasal catarrh. The bowels were constipated, and the child was miserable. The mother made a railway journey, taking the child with her to visit a friend. On the preceding evening the child was still sick. Next day she was listless.

The mother carried the child to a washbasin, and noticed that the child used only one hand. She consulted a doctor, and he diagnosed infantile paralysis. The sequence of events in this case was that the child had been infected with the germ at some period between one week and two weeks, previously. Let us estimate the incubation period at 10 days.

The disease directs attention to its presence by "a picture". It has, so to speak, a "sign manual". This collection of signs, taken together with the history, can be recognised. A common sign is pain in a limb. This will be accompanied by headache, perhaps, and feelings of fever; in fact the symptoms are those of influenza. This will occur in the so-called systemic stage when the virus has entered the blood-stream. The stage of infection, timed at the onset of the attack of the germ upon the tissues, is past. The child may be drowsy, miserable, disinclined to play, seeking the couch. Stiffness of the neck frequently makes its appearance at this stage, and has characterised recent cases. Vomiting very often marks the onset, and constipation may be present. All these signs, or some of them, combined perhaps with a nasal catarrh which has persisted for perhaps two weeks, are sufficient to justify a diagnosis of infantile paralysis. There will, of course, be a temperature.

The mother should now, if she has not done so earlier, call in a doctor. At a later stage, if the mother places her hands underneath the child's body and seeks to approximate the head to the feet, the child will frustrate the attempt. The mother should call the doctor when her child has been "off colour" for a few days, has a nasal catarrh, and a temperature, accompanied by a definite, persistent pain in a limb. The nasal catarrh is of importance, because the germ obtains entrance through the nasal mucous membrane, being breathed in, and infects the system through the nasal lymphatics [*Ed. This infection mechanism was, as we know, later disproved*]. But the absence of the catarrh does not invalidate the diagnosis if the other signs are present. Early recognition of the disease means cure, and delayed recognition and treatment too often a life-long paralysis. Paralysis of muscles or muscle groups is the chief danger in most cases. A diagnosis indicates the injection of serum obtained from convalescent patients. Fortunately there is now a supply of serum in Victoria. It is available at depots throughout the country, and is under the control of the poliomyelitis committee. Touching the affected muscles causes pain, and all unnecessary movement of the patient should be avoided. Life is threatened when the muscles of respiration are involved. In such a case the muscles moving the ribs and those which control the movements of the diaphragm are affected, and death occurs through failure of the respiratory movements.

Early Treatment Vital

The virus has a selective affinity for the nervous system, particularly that part of it which works muscles. Oedema or swelling produced by the presence of serous fluid of the nerve cells in the spinal cord occurs, and later a degeneration of the nerves. It is characteristic of the disease that when paralysis actually occurs many more muscles are immediately thrown out of commission than are finally paralysed. The extent to which recovery can take place depends upon the stage at which the serum treatment is instituted. If it is instituted in the so-called pre-paralytic stage – that is the stage of the disease before any definite paralysis is manifest – then the outlook is good. If the beginning of treatment lags beyond this stage, the results are at the very best problematical, generally bad, involving expensive and tedious treatment extending over years.

The serum of convalescent patients contains antibodies which kill the virus. If these antibodies reach the injured nerve cells when they are affected only by pressure due to the oedema they will recover. The results of treatment by serum in all parts of the world support this view, and they are confirmed by cases reported recently from New South Wales. But if the cells are dead recovery of the nerves cannot take place, and some degree of paralysis is inevitable. In considering the immediate home treatment, let us suppose a small child with a limb rendered helpless. The first thing the mother should do after sending for the doctor is to place the limb at rest in a position affording support to the muscles which have suffered the greatest damage. Bed and an arrangement of pillows fulfil this indication. The disease is conveyed by means of germs carried in particles of sputum or mucus coughed by a patient. To segregate the small sufferer, therefore, is urgent for the protection of other children in the household. Food, provided that it be good and plentiful, is unimportant in the prophylaxis. Cleanliness plays its part in the hygiene of this, as in every other, infectious disease. A simple precaution which every mother may take is to put her children through a regular daily toilet of the nose by means of a simple saline insufflation. The hygienic use of the pocket handkerchief, out-of-door sleeping, and the prompt treatment of nasal catarrh are practical prophylactic measures.

Post-Polio Network Office Co-ordinator's Report

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**George Laszuk
Office Co-ordinator**

Greetings once again from the staff and volunteers at the Parramatta Office.

Since the last *Network News*, April 2009, we have lost the services of volunteer Peter Gooley who has moved on to paid employment. We are grateful to have had Peter's assistance for four months. Fortunately, through our membership of the Volunteers Association, we have recruited another volunteer, John Doyle, who lives locally. John attends the office on Tuesdays and is proving to be a real asset to our Office as he brings with him extensive computer skills.

Since early June we have also been able to benefit from the skills of PPN member Elizabeth Woods. Some of you may know Elizabeth from the Northern Beaches Support Group which she originally started many years ago. Having since moved from that area, Elizabeth is now kindly convening the new Hills District Support Group (see details on page 37). Elizabeth will shortly be taking an extended leave of absence but we hope to welcome her back in the future.

I would like to take this opportunity to acknowledge the financial support which PPN receives from various Lions Clubs in NSW and, in particular, from the Mt Druitt Lions Club which, on our behalf, approaches other Lions Clubs to ask them to donate to PPN. This valuable support is vital to the ongoing funding of our Office. If any PPN members are involved with Lions Clubs, we urge you to encourage your Club to include PPN in their fundraising and donation projects.

Many members will not be aware of the Retirement Villages Project which I instigated, and which is now well underway. The project saw over 2,000 letters sent to Retirement Villages, Aged Care facilities and Nursing Homes in NSW to tell them about PPN and to offer our services to any residents who are polio survivors as we may be able to assist them to enhance their quality of life.

Barring unforeseen circumstances, the Office is generally open on Monday to Friday between 10:00 am and 3:30 pm. The current Office roster is:

PPN OFFICE ROSTER	
GEORGE	Monday, Wednesday and one "floating day"
FATMA	Monday and Wednesday
NOLA & JOHN	Tuesday
SHYLIE	Wednesday and Thursday
ELIZABETH	Friday

I look forward to meeting our members who will be attending the Country Conference in Wagga on 26 September (see pages 2 to 4).

Please Say Hello to Hamish

In the last *Network News* we reported that Carlie, our Office Administrative Assistant, gave birth on 6 March to a healthy baby boy, Hamish Aden. Carlie has brought Hamish into the Office a couple of times to introduce him to the staff and volunteers and he is now a thriving 5-month-old. We are looking forward to welcoming Carlie back to work in January. In the meantime, we thought you might like to see some family snaps of Carlie, her husband Daniel, and Hamish.



Helpful Resources

This regular series is aimed at bringing you information about services and products, that you might not otherwise be aware of, for people who are ageing and/or have a disability.

EnableNSW

Replacing the Provision of Aids to Disabled People (PADP) Scheme

On 12 May our Office Co-ordinator, George Laszuk, represented the Network at an EnableNSW information session for Non-Government Organisations at The Macquarie Hospital, North Ryde.

The purpose of the information session was to provide updated information on EnableNSW and changes to NSW Health's disability support programs.

NSW Health established EnableNSW to oversee the centralisation and the administration of PADP, as well as the Artificial Limb Service and the Home Respiratory Program.

All local PADP lodgement centres will eventually be closed, and there will be a single point of contact for all matters relating to PADP and other services provided by EnableNSW. Since July 2008, PADP has been in a transition phase to centralise the new service. The transition comes as a result of a NSW Government recommendation for a more consistent and cost-effective approach to the delivery of all NSW Health disability support services. These state-wide reforms will mean the delivery of these services will be integrated, consistent, cost-effective and equitable. All savings achieved through the reform of disability support services in NSW will be redirected back into the programs and used to purchase equipment for people with disabilities.

Further Information

Phone: 1800 362 253
Email: enable@hss.health.nsw.gov.au
Website: www.enable.health.nsw.gov.au



RailCorp

Proposed Changes to the Boarding Passenger Assistance Protocol for Disability and Commuter Groups

On 21 May George was out and about again, this time attending a presentation at RailCorp on the proposed revision to the Passenger Boarding Assistance Protocol (PBAP) to be implemented on the CityRail Network for current and future trains.

The presentation gave organisations like ours an opportunity to provide valuable feedback on the process of boarding assistance for passengers with disabilities. We were also provided with a brief outline on the intended changes.

One change will see RailCorp install flip-up seats, similar to those available on the buses. There are also plans to standardise the location for boarding the train by wheelchair passengers (for example, the 6th carriage) depending on the type and length of the train. For information about other changes please contact George at the Office.

George was able, on behalf of Network members, to provide insight into how the proposed changes could affect passengers with mobility disabilities.

RailCorp have stated that they are committed to improving train access for all commuters, but especially so for wheelchair passengers.

We hope that the items in this series are of interest and some use to you. If you know of any resources that might be helpful for members please pass the details on to the Office.

Companion Card Program

The Companion Card allows people with a significant and permanent disability, who require attendant care for the rest of their lives, to participate in community activities and events without discrimination.

What is the Companion Card Program?

The Companion Card has been developed to reduce existing discriminatory ticketing practices of many entertainment, leisure and recreation venues/activities and services.

People with a disability, who require attendant care type support, are often required to pay two admission and/or booking fees; one for themselves and one for their companion. This has the effect of increasing the admission and/or booking price for the person with a disability.

How does it work?

The card has a photograph of the cardholder and can be presented when booking or purchasing a ticket at events and venues, provided the cardholder requires attendant care support in order to participate at that particular activity. The participating venue or service will issue the cardholder with a second ticket for their companion at no charge.

Who is Eligible

The Companion Card is issued to residents of NSW with a significant and permanent disability who are unable to participate in most community based activities without significant assistance.

The card is only provided to people if their level of support is life-long and they meet all of the eligibility criteria described below. The card is not provided to people who require social support, assurance or encouragement.

The Companion Card is not means tested.

It will be issued to people who are assessed as meeting all of the following eligibility criteria:

- ❖ severe or profound and permanent disability;
- ❖ unable to participate in most community-based activities without significant assistance with:
 - mobility
 - communication
 - self care
 - planning and
 - where the use of aids and other technologies does not meet those needs;
- ❖ their level of support is lifelong.

The Companion Card is not for every person who has a disability. It will only be issued to people who are able to demonstrate that they will require attendant care for the rest of their life. There may be circumstances whereby a person may use the support of a companion but will not qualify to receive a Companion Card.

Application Form and Further Information

Phone: 1800 893 044

Email: companioncard@nds.org.au

Website: www.nds.org.au/nsw/companioncard.htm (NSW website)

Website: www.companioncard.org.au (National website with links to all other state websites)



Look out for this sign when you next book, or visit the Companion Card Affiliates web page www.nds.org.au/nsw/companioncard/affiliates.htm to view all participating organisations in NSW

Support Group News

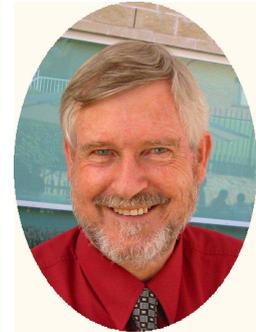
Neil von Schill

Support Group Co-ordinator

Phone: (02) 6025 6169

Fax: (02) 6025 5194

Email: support@post-polionetwork.org.au



As part of our endeavour to better service the needs of Support Groups, in March our Office Co-ordinator, **George Laszuk**, visited the **Blacktown/Blue Mountains Support Group** hosted by long-serving convenor, **Bernie O'Grady**. The group had a long and fruitful discussion with many issues canvassed and suggestions made. George and I will implement some of the initiatives suggested.

In May, George and I ventured up the North Coast in unseasonal weather conditions but managed to stay a day ahead of torrential rain and flooding rivers. Our first stop was to visit the **Port Macquarie Support Group** at the Golf Club. **Pat and Gerry Adamson** made us very welcome at a well-attended luncheon. It was wonderful to catch up with old friends and make new acquaintances. May I thank all members who made the effort to attend the meeting which was scheduled to fit in with our busy itinerary.

The next day we travelled north to Urunga for another very important gathering. On the initiative of **Ken Dodd and George Laszuk** there was a desire to renew interest in a support group on the mid north coast. Invitations were sent to members living in the **Nambucca, Bellingen and Coffs Harbour Shires** to attend a meeting at Urunga. The need was very evident because we had an excellent response with eighteen people in attendance at the meeting. The group decided that they would re-form under the name of **Coffs Coast Support Group**. Meetings will be held at **10:30 am** on the **first Wednesday of every second month**. This year, the first meeting was held in August and this will be followed by meetings in October and December and then recommence in February 2010. The venue will be the **Urunga Golf Club** where the management has made a room available at no charge. This was a fantastic outcome and I know that members have ideas for the future development of the group. The Coffs Coast Support Group will become a viable and progressive voice for polio survivors in the area. May I pay special tribute to the efforts of convenor, **Ken Dodd**, and his colleagues in making this initiative happen. Please contact Ken on 02 6655 1112 for any further details.

A very successful inaugural meeting to establish a **Support Group** in the **Hills District** of northern Sydney was held on Tuesday 21 July at the West Pennant Hills Sports Club in New Line Road, West Pennant Hills. I am very pleased to announce that **Elizabeth Woods** has accepted the role of convenor for the group and she will be assisted by **Margaret Whittle**. The group are meeting at **10:30 am** on the **second Wednesday of each month** at the **West Pennant Hills Sports Club**. If you are interested in attending future meetings please talk to Elizabeth who can be contacted on 02 9896 7818. Members living in the vicinity are urged to consider attending future meetings.

Finally, a reminder about the **Country Conference** this year which is being held in **Wagga Wagga**, hosted by the local Support Group. The Conference will be held on **Saturday, 26 September 2009** and the venue is the **Country Comfort Motel** on the corner of Tarcutta and Morgan Streets in central Wagga Wagga. Full details of the **Conference Program** with its excellent line-up of presenters appear on **pages 2 to 4**. Please return the enclosed **Registration Form** as soon as possible if you are interested in attending.

Polio Particles

Mary Westbrook

Polio Particles, written by Mary Westbrook, reports information and stories about polio, post-polio and disability issues of interest to polio survivors. These include press reports, research findings, book reviews and updates on polio eradication and immunisation. *Polio Particles* is syndicated in post-polio newsletters internationally.



Effective resting

Rancho Los Amigos Post-Polio Support Group Newsletter June 2009 reported a talk given to the group by post-polio specialist, Dr Vance Eberly. In the course of his talk he discussed the overuse of post-polio syndrome muscles that causes muscle pain and twitching. He said that resting is very important both as a preventive measure and when you are suffering the effects of overdoing and emphasised the importance of lying down to rest. Dr Eberly stated that, “*Many people need to break up their day; they lie down for 15 or 20 minutes, two or three times a day. That helps especially with back pain. Post-polio syndrome frequently affects your spinal muscles and your anti-gravity muscles. So sitting down doesn’t help because you are using those muscles to sit upright. If you didn’t use them you would flop over. Polio survivors need to get out of the chair and lie down to rest those muscles.*”

Research into polio virus fragments in polio survivors

Each year the Research Fund of Post-Polio Health International (PHI) in St Louis makes an award. The 2009 award of \$US25,000 was given to a group of researchers at the University of Insubria Medical Centre, Varese, Italy headed by Antonio Toniolo, Professor of Microbiology and Virology. The grant will fund a study *Persisting Noninfectious Fragments of Poliovirus in PPS patients: Virus Detection and Susceptibility to Antiviral Drugs*.

Past research has detected fragments of poliovirus in the cerebrospinal fluid of PPS patients. It is speculated that these may trigger a chronic inflammatory response in the body which may be responsible for PPS symptoms. If this is so an antiviral treatment may be possible. Toniolo and his team plan to investigate the genetic structure of the persistent poliovirus fragments found in people with PPS and compare them to wild-type polioviruses. They will then test the susceptibility of the fragments to antiviral drugs. The board president of PHI, Lawrence Becker, said that the research team impressed PHI “*as having real promise for tracking down the etiology of post polio syndrome. And if it turns out that these viral fragments play a major causative role, the study will not only help develop an important diagnostic tool, but may point the way toward an effective treatment.*” This could benefit many people because as PHI points out there are over 20 million polio survivors worldwide and PPS is the world’s most prevalent motor disease.

Finding words to describe symptoms like fatigue

Polio survivors often say that that they find it hard to explain to others what the fatigue they experience feels like; that it isn’t just the same as what able-bodied people describe as feeling tired and furthermore fatigue comes in various forms. Are we right? Some support for the existence of distinct types of fatigue comes from a study comparing the way people with chronic fatigue syndrome (CFS) and the people in the general population perceive pain. This is relevant to polio survivors as a number of researchers have described the fatigue of CFS as similar to that of PPS and some have speculated that CFS is caused by

a virus of a similar type to the poliovirus. The study was conducted by Leonard Jason and a team of researchers who reported their findings in *Disability Studies Quarterly*, 2009.

Using a questionnaire they developed the researchers found that people with CFS distinguished five types of fatigue. These were: 1) Post-exertional fatigue exemplified by statements such as you feel physically drained after mild activity, and minimum exercise makes you tired; 2) Wired fatigue eg it's hard to sleep because you are tense and agitated, your body feels overstimulated when very tired; 3) Brain-fog fatigue eg thinking is hard work and muddy, you misplace items and cannot remember things; 4) Energy fatigue eg you do not have energy to do anything, you lack the energy to talk to anyone; and 5) Flu-like fatigue eg you have muscle aches or pain all over your body, you feel like you have a high temperature or fever. In contrast the able-bodied participants' view of fatigue was that there is only one generalised type of fatigue, primarily a feeling of drowsiness or tiredness which may be accompanied by some of the symptoms the CFS group described but these were not experienced as separate types of fatigue.

My hunch is that polio survivors would make somewhat similar distinctions. The researchers consider that understanding the distinct types of fatigue patients may be experiencing will help health practitioners provide individualised treatment options. Understanding types of fatigue will help patients communicate with their family, friends and health-care providers. I remember that reading the distinction Dr Lauro Halstead made between various types of post-polio pain was a liberating experience for me because I now had a vocabulary to communicate with health professionals and family. Halstead distinguished three types of polio pain. He described type 1 pain as post-polio muscle pain which *"is felt only in muscles affected by polio. It can occur both as a superficial burning discomfort or as a deep muscle ache ... the deep pain is often characterised by muscle cramps, while the superficial pain is sometimes associated with fasciculations (twitching), a crawling sensation, or extreme sensitivity to touch"* (*Managing Post-Polio; A guide to living well with post-polio syndrome*, page 38). At its worst I find this crawling pain almost unbearable yet none of the pain vocabulary I had learnt seemed to justify calling it pain until I read Halstead. [Ed. The second edition of Halstead's book is available from the Network (see the back page of this *Network News* for details) – please contact the Office to order].

Polio elders

Living with Polio in the 21st Century was title of the 10th Post-Polio Health International Conference which was held in Warm Springs this year. Sunny Roller, a polio survivor and researcher, gave a talk on her research into polio elders' life experiences of coping with polio. Elders were selected as being highly regarded role models within their PPS support groups in the USA. All were over 65 and more than 50 years past the onset of their disability. From her interviews with elders Roller found that:

- Major issues throughout these polio survivors' lives included: *"Achieving and maintaining independence which requires diligent effort; fighting shame and creating a positive self-image with a disability; and reconciling social and functional losses."*
- Elders' perception of being disabled from polio had altered over the years. *"The years with polio during childhood, adolescence and as an adult were not comfortable. ... Before developing PPS in mid-life elders had worked hard using their 'lens of difference', a self-perception that rejected the shame and prevalent social stigma of disability. High achievement was crucial. Later in life they became more willing to look at their lives through the 'lens of disability', more fully embracing their disability as part of their overall personal identity. In doing so they became more content with this new self-perception and life in their retirement years."*

- The main coping strategies survivors had used were “*having a strong social support system, enjoying life, being optimistic, self-acceptance, assertiveness, education and spirituality.*”

“Ironically”, Roller comments, “*growing older with greater disability has offered this group a fresh sense of not only comfort, but also liberation. ... Once retired, there was no longer a need to prove oneself in the mainstream workplace and keep up with non-disabled competitors. ... In many important ways, life was reported as better in old age than it ever was in youth.*”

Roller also commented on the wisdom of the polio elders but noted that “*this group’s strong suit was not necessarily sympathetic and compassionate love for others. It may be that for this group, because of their life experience with disability, survival skills often had to trump compassion. Early on they learned that they had to work through the pain they may have felt physically through the years and rise above it. They had no time to feel sorry for themselves if they wanted to make it in society ... Rehabilitation professionals and parents were tough on kids with polio because they were seen as having much weakness to overcome. Hence this study’s subjects warned others about not associating with negative people too much. They would drag them down. Because they had to go beyond their own self-pity to overcome disability, they did not approve of self-pity in others and expressed low tolerance of ‘whiners’. As one participant said, life with polio could make a person ‘damn tough’.*”

No time for tears

Roller’s comments on the historical reasons for the polio elders’ lack of compassion came to mind when reading *Bracing accounts: The literature and culture of polio in postwar America*, a book by Jacqueline Foertsch (published by Fairleigh Dickinson University Press, 2008). Various sections of the book discuss what women’s magazines wrote about polio (titled, “*A battle of silence*”), what novels covered (titled, “*Crippled by history*”) and what memoirs reported (called, “*No time for tears*”). *No time for tears* was also the title of Charles Andrew’s 1951 book about his ten-year old son Chuck’s attack of polio. Foertsch writes, “*When finally allowed to visit [the hospital], Chuck’s parents cheerfully invalidate his fear and sadness*”. Later when Chuck learns he may not be home for Christmas his father wrote, “*He screwed up his face and began to cry ... We remained immobile until he got under control*”. Foertsch commented that Andrews attributes Chuck’s near-total recovery to his “*blustering philosophies about ‘ignoring handicaps’ ... while in fact Chuck may have done as well as he did despite his parents’ emotional coldness and misguided doctoring*”. Many other memoirs Foertsch describes and many Network members’ personal stories of their hospitalisation contain such incidents of ignoring or punishing children’s distress.

Roller suggests that the wisest of the polio elders she studied (see previous article) were “*the ones who revealed that their experience with disability is now, in later life, making them more compassionate toward others with a disability, because they have grown in greater self-acceptance with their own disability*”.

Polio survivor returns to India

Gautam Lewis was born in India in 1977. He contracted polio when he was 3 years old and was abandoned by his mother at Mother Teresa’s orphanage in Calcutta. Here he met a young British volunteer, Patricia Lewis, who adopted him when he was 7. In England he attended exclusive schools: Hill House with Prince William, and Bedales. “*It is ironic that I came from the poorest of poor families in Bengal and ended up studying with the richest children in England*”, Gautam said. Following university Gautam has had a career in the music industry managing bands, run an events company and set up *Freedom in the Air*, a

flying school for disabled people in the UK. Gautam is now an ambassador for *Rotary International* and for the *Global Polio Eradication Initiative*. Gautam, who uses crutches, regularly returns to India to take part in the polio eradication campaign. A 25-minute film of his experiences, *Passport to Polio*, was recently shown on Al Jazeera TV and may be viewed on the website (in English) <<http://www.freedomintheair.org/?p=1545>> [Ed. also available on YouTube <www.youtube.com/watch?v=hM1-SM3jvjl>]. The film follows Gautam's emotional visit to the orphanage in Calcutta where he was abandoned and to a treatment centre for children with polio. In an interview with *Ouch*, the BBC disability program (9/4/09), Gautam said he had not wanted to revisit his past "*because it was an unstable childhood full of heartache, in a place which provides life and not much else ... I was lucky to survive [polio] in a time and place when 1 in 5 children were dying of it. Part of me thinks it's brilliant that I had polio, because without it the rest of my life wouldn't have happened. But I've had to work hard to be fit and, above all, independent*". I recommend the film which besides giving insights into the frontline of the battle against polio today also has scenes of the treatment of polio reminiscent of our past. Remember having plaster splints made?

Polio Free Certified stickers

The National Highways and Motorways Police in Pakistan have launched a *Polio Free Certified* car sticker campaign in collaboration with UNICEF and other agencies involved in polio eradication. It is hoped that this initiative will result in children in transit during polio immunisation rounds being identified and vaccinated. A polio vaccination facility information has also been made available via the toll free emergency helpline (Reported in *The News from Islamabad*, 21/11/08).

New medical assistive device?

An American company has produced the *Palm Pistol*, a gun for disabled people "*who may have limited strength or manual dexterity. Using the thumb instead of the index finger for firing, it significantly reduces muzzle drift, one of the principal causes of inaccurate targeting*". The company is trying, so far unsuccessfully, to have the gun marketed as a medical device for which the US government will reimburse seniors who buy the \$US300 firearm. The manufacturer says that it's something people with arthritis and other disabilities "*need to assist them with daily living ... no more or less than for a walking aid or wheelchair*". Only in America! (Story from *New Scientist Tech* 16/12/08).



Wheelchairs Giveaway

One of our members has kindly donated 2 manual wheelchairs. One small and one large. If anyone is requiring a wheelchair please contact the PPN Office on (02) 9890 0946 to discuss delivery.

The chairs are at Berowra, near Hornsby, for people who live in the Sydney metropolitan area. If you live in a country area we would have to work out an arrangement for transport.

Exoskeletons are on the March

I recently spotted this article originally published by the Institute of Electrical and Electronics Engineers (IEEE) and, harking back to Darren Pereira's excellent presentation (see pages 6 and 7), thought it might be of interest to members. Although HAL is still undergoing development and not yet available in Australia, it signals the future. Other organisations working on exoskeleton designs include Berkeley Bionics, Raytheon and MIT.

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News Report from Taipei-based reporter, Yu-Tzu Chiu – 17 August 2009

An army of exoskeletons is coming. And according to their inventor, Professor Yoshiyuki Sankai of the University of Tsukuba, in Japan, they're making a difference in the lives of disabled people.



Speaking at the International Conference on Intelligent Robotic Technology and Business, held earlier this month in Taipei, Taiwan, Sankai proudly described how the robotic exoskeleton suit HAL (short for Hybrid Assistive Limb), helped a 46-year-old man whose left leg was withered by polio when he was 11 months old.

HAL reads electric signals at the surface of the skin that are generated by the muscle beneath and then uses them to guide the movement of robotic limbs strapped to a person's real limbs, thereby multiplying their strength.

The polio patient's withered left leg generated extremely weak bioelectric signals at first, and the robotic limb remained unmoved. Ten days later, with HAL's assistance, the patient moved his left leg based on his own intention. "He cried", says Sankai.

Sankai suspects that in the past 45 years, the patient's brain had rarely generated the signals needed to move his left leg. After the patient used HAL, the levels of signals strengthened and became detectable. Sankai says that similar phenomena were observed when applying the HAL suit to patients with spinal cord injuries. Starting in late April, his team began measuring bioelectric signals in polio and stroke patients before and after using HAL. They hope to record data over a period of 8 to 12 months. An analysis of how the brain adapts to HAL will be taken into account to improve the exoskeleton's operation, says Sankai.

In Japan, more than 20 sets of various HAL exoskeletons are in use at hospitals and rehabilitation centers, Sankai says. The facilities lease the robots from Sankai's company, Cyberdyne, for about US \$1,700 per month on average.

"It's worthwhile, because a suit can be used for eight patients per day", he says, adding that the service could possibly be cheaper once the market for the exoskeletons increases.

Sankai, who is Cyberdyne's CEO, expects to supply 80 to 90 suits in Japan in October. At the end of September, 10 sets of HAL suits will be delivered to Denmark to be used by nurses who care for elderly people. The suits should enhance the nurses' strength, helping them to move patients.

More versions of HAL are in the works, says Sankai. Following HAL's use by a man injured in a car wreck to climb the 4,164-meter Breithorn Mountain, in Switzerland, the company decided to develop a weather-resistant outdoor exoskeleton. Sankai says the company will also be introducing a HAL with significantly smaller and lighter batteries this fall at an event in Kyoto.



2009 Post-Polio Network Seminar Program

<p>Saturday 26 September 2009</p>	<p>Country Comfort Motel <i>Morgan & Tarcutta Streets Wagga Wagga</i></p>	<p>Country Conference Simon Mathieson, Polio Services Victoria Dr Louis Baggio, Rehabilitation Physician Sue Gorman, IDEAS, Tumut Brian Wilson, Post-Polio Network (NSW) Mary-ann Liethof, Polio Network Victoria <i>Full details appear on pages 2 to 4</i></p>
<p>Saturday 28 November 2009</p>	<p>Burwood RSL Club <i>96 Shaftesbury Road Burwood</i></p>	<p>Annual General Meeting and Seminar The Network is 20 years old in 2009 Looking Back, Looking Forward A review of past achievements and future vision <i>Further details will appear in the next Network News</i></p>

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Mary Westbrook	Q's about polio & pps	askmary@post-polionetwork.org.au	---

About the Network

The Post-Polio Network (NSW) Inc was formed in 1989 by polio survivors for polio survivors.

It is a self-help, self-funded organisation run entirely by volunteers. The Network provides information about polio's late effects and supports those who may be affected now or in the future. The Network conducts regular Seminars and Conferences, publishes *Network News*, fosters the establishment of regional Support Groups throughout NSW and the ACT, and maintains a comprehensive website.

Polio survivors, their family members and friends are all welcome to join the Network, as are health professionals and anyone else who supports the Network's aims. Membership provides information and support that can maximise the physical and psychological quality of life of polio survivors.

If you live in Australia, we can post you a free Information Kit and Membership Application Form. The Kit includes a copy of our booklet *Helping Polio Survivors Live Successfully with the Late Effects of Polio* which explains the late effects of polio and details the many benefits of Network membership. This booklet can be emailed to those enquiring from overseas.

The annual membership subscription (payable in Australian dollars only) is \$10 not employed or \$20 employed. On first joining, new members also pay a \$5 once-off joining fee. Those initially joining between 1 April and 30 June in any year are deemed to be financial until 30 June the following year. Membership renewal is due on 1 July each year and members are alerted to their financial status with each Network mailing. Over 80% of the Network's income which is used to provide its services comes from membership subscriptions and donations.

Resources for Members

On joining the Network, members are issued with free resources including a brochure *Hospital, Medical And Dental Care For The Post-Polio Patient – A Handy Reference*, and a *Medical Alert Card* which can be carried in the wallet.

The Network also stocks various publications which further describe the late effects of polio and their management. The prices quoted below are for Network members and postage is included. To order, just write to the Network – please make cheques / money orders payable to Post-Polio Network (NSW) Inc.

Books etc (* indicates Post-Polio Network publication)	Size	Cost
<i>Managing Post-Polio: A Guide to Living and Aging Well with Post-Polio Syndrome</i> Second Edition Edited by Lauro S Halstead MD (<i>see description below</i> ☞)	288 pages	\$40.00 <i>incl 10% GST</i>
<i>A Practical Approach to the Late Effects of Polio</i> Charlotte Leboeuf	39 pages	\$2.50
* <i>Living with the Late Effects of Polio</i> Conference Proceedings, edited by Gillian Thomas	170 pages	\$29.00
* <i>Polio – A Challenge for Life – The Impact of Late Effects</i> Report: Survey of Members, Merle Thompson	54 pages	\$12.00
* <i>Post-Polio Network - Helping Polio Survivors Live Successfully with the Late Effects of Polio</i> , Dr Mary Westbrook	12 pages	\$3.00 <i>1st copy free</i>
The Network has its own four-colour enamelled badge featuring a stunning polio virus design. The badges are suitable for men or women. Each badge comes with a description of the virus and information about the Network. Not only is the badge a great fashion statement, it is an innovative way to promote the Network.	23 mm x 23 mm	\$5.00 <i>plus \$1 postage</i>

☞ ***Managing Post-Polio: A Guide to Living and Aging Well with Post-Polio Syndrome (Second Edition)***

The second edition was published in 2006. Editor Lauro Halstead writes about the rationale for this edition:

As with the first edition of *Managing Post-Polio*, the major goal of this volume is to summarize the best advice available to diagnose and manage PPS in an easy-to-read, authoritative format for polio survivors, their families, and friends, as well as for health care professionals. The majority of contributors to this book are either polio survivors or experts who have worked closely with polios in clinical settings.

Another important objective of the earlier edition was to reach as wide an audience as possible – an objective that far exceeded our expectations with more than 15,000 copies in circulation. As news about PPS spread, the demand for more information continued to grow. This new edition is in response to that continued demand for information. Also, we have added a new theme to this edition – aging with disability, as once again polio survivors are “pioneers” – the first large group with a chronic physical disability to undergo aging. Since the initial edition, we are all nearly 10 years older, and, hopefully wiser. Quite possibly, we are also more disabled and, therefore, more challenged. It is my hope that this book will help guide us as we journey along this new path together.

Audio tapes of many of the Network Seminars and Conferences held since 1989 are also available at reasonable prices. For further details please contact the Network.