



POLIO NSW INC (formerly Post-Polio Network (NSW) Inc)

NETWORK NEWS



Incorporating – Polio Oz News

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President's Corner

Gillian Thomas

Welcome to another combined issue of Network News and Polio Oz News which this time includes a report on the presentations made at our mid-year Seminar together with other regular features.

It is Membership Renewal time and we would like to thank the many members who have already renewed their 2012/2013 membership.

Enclosed, you will find one of two forms, depending on your financial status. If you are currently paid up to 30 June 2012 (your address sheet reads Renewal Due On: 1/07/12) you will find a Membership Renewal Form enclosed for the period 1 July 2012 to 30 June 2013. Could you please confirm, complete, or amend your details as given on the Form, and return it with your subscription to the Treasurer at the Polio NSW Parramatta postal address above. A growing number of members appreciate the ability to pay their membership subscription via internet banking. If you take up this option, please ensure your name is recorded on the payment and email the payment transaction details to <treasurer@polionsw.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 – *please don't tear off and return only part of it.*

There is still a number of people whose annual subscriptions are overdue, and so their address sheet reads Renewal Due On: 1/07/11 (or earlier). In this case, the Membership Renewal Form covers more than one year's membership. We would appreciate prompt payment of the outstanding dues, together with the current dues, to ensure that you continue to receive your newsletter and other mail-outs.

Polio NSW is self-funded and needs your continued support to enable us to keep providing services to polio survivors and their families.

If you are already financial beyond 30 June 2012 (again as shown on your address sheet), you will receive a Membership Update Form which gives your current details but does not request payment of a membership subscription. Please check your details and be sure to return the Form if any amendments are required.

Finally, I was recently contacted by Heather Hubert who contracted polio in 1938 when she was three years old. Heather spent some time in the Children's Hospital in Brisbane before being transferred to Sister Elizabeth Kenny who managed to help her body enjoy a reasonably normal life. Heather has been contacted by Allan Hildon, Lecturer and Programme Head for MSc in Health Care Management, School of Health and Human Services, University of Essex, UK. Allan has had a long term interest in the work of Sister Elizabeth Kenny and has asked Heather to research any people who were treated by Sister Kenny or by her methods. Please contact Heather directly by phone on 02 6566 5519 or by email at <heatherhub@ecopost.com.au> if you are were treated by Sister Kenny and are interested in contributing to Heather's research.

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Polio Eligible for Enhanced Primary Care Program

In Summary: Medicare rebate for a maximum of five services per patient each calendar year, with out-of-pocket costs counting towards the extended Medicare safety net

- A patient must have a GP Management Plan (GPMP) and Team Care Arrangements (TCAs) (or a multidisciplinary care plan for residents of an aged care facility).
- Your GP will decide whether you would benefit from these services and, if so, will refer you for appropriate allied health services.
- Allied health professionals must be registered with Medicare Australia

Who is eligible?

You may be able to claim Medicare rebates for allied health services if you have a chronic (or terminal) medical condition that is being managed by your GP under both of these Medicare Chronic Disease Management (CDM) items: a GPMP and TCAs.

Chronic Medical Conditions

A chronic medical condition is one that has been (or is likely to be) **present for six months or longer**. It includes, but is not limited to, conditions such as asthma, cancer, cardiovascular disease, diabetes, **musculoskeletal conditions** and stroke.

Management of Your Condition

Care plans can help you and your GP manage your medical condition by identifying your needs and the action required.

If you have a chronic (or terminal) condition, with or without complex care needs, a GPMP will enable your GP to provide a structured approach to your care. It is a plan of action in which you agree management goals with your GP.

If you also have complex care needs, TCAs will enable your GP to collaborate with at least two other care providers involved in your treatment. TCAs will identify who needs to be involved in your care and help coordinate the team-based approach.

Individual allied health services

Once you have a GPMP and TCAs in place, you can be referred for up to five allied health services each calendar year. It is important to understand that only your GP will decide whether you should be referred for these services.

The five services can be provided by a single allied health professional or shared across different professionals.

You can request that your GP refer you to an allied health professional you already know, or your GP can recommend one.

Allied health professionals need to meet specific eligibility criteria and be registered with Medicare Australia.

Eligible Allied Health Professionals

Aboriginal health workers audiologists chiropractors diabetes educators dieticians exercise physiologists
mental health workers occupational therapists osteopaths physiotherapists podiatrists psychologists
speech pathologists

Private health insurance

If you have private health insurance, you will need to decide if you wish to use Medicare or your private health insurance to pay for these services. You cannot use private health insurance ancillary cover to 'top up' your Medicare rebate.

Claiming

Allied health professionals, like doctors, are free to set the level of their fees. If your allied health provider bulk bills, there will be no charge for these services. If not, you will be charged a fee and you can claim the rebate from Medicare.

Out-of-pocket expenses for these services count towards the extended Medicare safety net.

If you are unsure, or lose track of how many allied health services you have claimed in a calendar year, you can check with Medicare Australia on 132 011.

More information

More information is available at www.health.gov.au/mbsprimarycareitems
If you have any questions, ask your doctor or practice nurse.

Recommendations from Polio Roundtable Forum

In order to secure ongoing funding and enhance services for polio survivors around Australia, the Management Committee of Polio Australia has been lobbying the Federal Government. To effectively lobby, education of Parliamentarians and others was undertaken to increase their awareness of the Late Effects of Polio/Post-Polio Syndrome (LEOP/PPS). On realising how low is the level of awareness of health professionals and the wider community of the LEOP/PPS, the House of Representatives Standing Committee on Health and Ageing Committee held a Roundtable Forum on 30 March 2012.

The Committee invited key stakeholders involved in the diagnosis, management, support and advocacy for those with LEOP/PPS. These stakeholders included Gillian Thomas, President Polio Australia and Polio NSW, Dr John Tierney OAM, National Patron, Polio Australia Inc and a member of the Management Committee, Polio NSW, as well as office bearers from other state polio associations.

On 4 July the Committee released the following three recommendations which resulted from the Roundtable Forum:

Recommendation 1: The Committee recommends that the Australian Bureau of Statistics and/or the Australian Institute of Health and Welfare establish mechanisms through inclusions of appropriate questions in existing health and/or disability surveys to estimate and report on the size of the population of polio survivors living in Australia, and the proportion of that population experiencing the late effects of polio/post-polio syndrome.

Recommendation 2: The Committee recommends that the relevant National Boards, in consultation with key stakeholders including peak professional bodies, medical/health educators and training providers, seek to ensure curricula for students includes information on the late effects of polio/post-polio syndrome, to raise awareness of the condition as a possible diagnostic outcome and of best practice for treatment and management.

Recommendation 3: The Committee recommends that Medicare Locals actively engage with Polio Australia and state-based post-polio associations, with state and territory government departments of health, and with general practitioners to promote activities which will raise awareness of the late effects of polio/post-polio syndrome:

- among practicing health professionals through continuing professional development; and
- in the community through patient education, noting the need to tailor communication to enhance engagement with specific population groups taking into account demographic factors such as age and cultural background.



Flow on from the Roundtable Forum

The Australian Medical Association has picked up on the release of the Health and Ageing Committee's Discussion Paper and published some details in an article dated 16 July 2012 on the Australian Medicine Online website <ausmed.ama.com.au/node/3537>.

Polio sufferers going undiagnosed

A parliamentary committee has been told that more than 150,000 people may be at risk of suffering the late effects of polio even though the country has been declared free of the devastating illness for more than 12 years.

In a discussion paper intended to raise awareness of the condition, which can cause debilitating physical and neurological symptoms, the House of Representatives Health and Ageing Committee said that although there are no reliable estimates of the prevalence of the condition, it was likely that thousands of Australians were unknowingly suffering from late effects polio or post-polio syndrome.

In the paper the Committee said evidence suggested between 20,000 and 40,000 people were infected by polio between the 1930s and 1960s and could be at risk of developing late effects polio or post-polio syndrome (LEOP/PPS), while immigrants coming from areas where the disease has only more recently been eradicated or continues to be endemic may also suffer from the condition.

At a public roundtable to discuss the issue, Dr Stephen de Graaff, Director of Pain Services and Senior Rehabilitation Physician at Epworth Healthcare, estimated that between 0.6 and 0.8 per cent of the population were polio survivors, suggesting that between 132,000 and 176,000 people may be at risk of the condition.

The Committee said one of the factors making it hard to accurately gauge the prevalence of late effects polio and post-polio syndrome was that they were difficult to diagnose – a problem exacerbated by the lack of clear diagnostic tests and limited awareness among health professionals of the conditions.

The discussion paper said that early diagnosis was essential if patients were to derive the greatest benefit from treatment, but this was hampered by lack of a definitive diagnostic test.

It heard evidence from sufferers that many had been misdiagnosed with chronic fatigue syndrome, and reported that *“many people living with LEOP/PPS continue to experience frustration, often waiting years to receive the correct diagnosis”*.

The Committee heard that the effects of the affliction were substantial, including physical impairment as well as social, emotional and financial effects.

Committee chair, Labor MP Steve Georganas, said that *“LEOP/PPS and its [sic] impact on the lives of sufferers, their families and careers have gone largely unrecognised in Australia”*.

“The Committee was particularly concerned about the lack of information on the prevalence of LEOP/PPS and the size of the population at risk,” Mr Georganas said. “While the Committee understands that basic research is needed to improve diagnostic capability which will enable accurate determination of prevalence, in the meantime there is still a crucial need to establish a mechanism to gauge the possible extent of LEOP/PPS in Australia and the population at risk.”

The Committee recommended that the Australian Bureau of Statistics and the Australian Institute of Health and Welfare collect data on the size of the population of polio survivors, while medical schools include LEOP/PPS in their curricula and Medicare Locals work with groups such as Polio Australia to raise awareness of the condition both among health professionals but also the broader community.



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

The Australian Polio Register was established by Polio Australia in October 2010 to gather information on the numbers of polio survivors living in Australia today, whether or not they contracted polio in this country. There are currently almost 1,800 polio survivors on the Register and this number increases daily. To make the Register truly reflective of the unmet need for polio services throughout Australia, all State polio networks are urging every Australian polio survivor to join the Register which is available on Polio Australia’s website at <www.polioaustralia.org.au>. The Australian Polio Register form can either be completed online or downloaded (by you, or a friend with internet access) for completion and subsequent return to Polio Australia.

Polio NSW Office Co-ordinator's Report

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**George Laszuk
Office Co-ordinator**

I would like to thank and dedicate this report to all the people and organisations that make it possible for Polio NSW to run this office, for without them we would not be able to exist here in Parramatta.

Firstly, special thanks must go to **The Northcott Society** who not only supply us with an office but also give us administration and IT support in the everyday operation of our office. In addition to this Northcott make available seminar rooms for functions and conferences at very reasonable rates. The cooperation and friendliness of the staff at Northcott is extraordinary, where nothing is too much trouble when assistance is required.

Another generous group of organisations which has assisted us financially is the **Lions Clubs of NSW**, especially **The Lions Club of Mount Druiitt** which has taken our organisation on as a club project and has raised in excess of \$70,000 to support our operations since the office opened.

A big thank you must go to our dedicated volunteers and staff who work in our office. These valuable people come in on rostered days and I would like to introduce you to them again.

Monday	Tuesday	Wednesday	Thursday	Friday
Carlie	Nola	Shylie & Fatma	Shylie & John	Carlie

I work three days a week, generally on Monday-Wednesday, and fill in on other days as necessary. Without our dedicated staff and volunteers, having the office open every day would be impossible.

Last but not least, the Management Committee should be congratulated for their foresight and support in opening this office many years ago. The office in Parramatta now plays an important part of Polio NSW's ability to service our members and relieves various tasks from overworked Committee members (for example distributing information kits to polio survivors and the general public), provides a more accessible location for members to visit and provides Polio NSW with a sense of identity in the eyes of the public.

We all must remember that the members of our Committee are nearly all polio survivors and are getting on in years, therefore their ability to continue the huge work load in running our organisation is diminishing.

Our biggest obstacle in keeping our office viable is funding, as you are probably aware we receive no government assistance and rely solely on donations and subscriptions.

So, in conclusion of this report, if any member can offer any assistance or give us any ideas in raising much needed funds please contact me or any member of the committee.

Polio NSW Support Group News

Last September Neil von Schill advised the Management Committee that, for unexpected health reasons, he unfortunately had to resign from his positions of Secretary and Support Group Co-ordinator. Neil's commitment to the Support Groups and their conveners has been invaluable and he will be greatly missed by the Network.

As I have had exposure to Support Groups whilst accompanying Neil on many occasions to Support Group meetings in both regional and metropolitan areas, the Management Committee have decided that I should take over this role on a temporary basis.

As a former Support Group member, I am well aware of the value of Support Groups to people who have had polio, and am looking forward to working with you.

Over the coming months I will endeavour to be in contact each group and, in the meantime should you have any problems that I may be able to assist you with, please ring me at the office on (02) 9890 0946 or out of hours on 0412 082 983.

George Laszuk
Office Co-ordinator



We are delighted to advise members that Polio NSW long serving Committee member, Alice Smart, has been recognised in a recent article for her achievements and contributions to RPAH Airways Support Group. Congratulations Alice.



Alice Smart

Alice Smart is the coordinator of the Royal Prince Alfred Hospital (RPAH) Airways Support Group in Camperdown, Sydney. The Group was set up in 1997 and has been extremely important in the lives of patients with respiratory disease, providing participants with an in-depth knowledge of respiratory illness and its management. It has also provided patients and carers with the coping skills required to manage the issues pertaining to living with chronic disease on a daily basis. Alice has had asthma since childhood and suffers from post-polio syndrome. As a result she has had a long-term association with RPAH through many admissions and surgeries. Despite this, Alice is committed to supporting others with lung disease and has worked tirelessly since she took over the running of the RPAH Airways Support Group. She is a "mover and a shaker" and has managed to raise large sums of money for new equipment which is now utilised in both the ward and outpatient gym settings. This has been achieved primarily by her organisation of raffles which have always included interesting prizes.

*Printed from Lungnet News,
Official Newsletter of the
Australian Lung Foundation.
Written by Lissa Spencer
and Bill Zafiroopoulos,
Pulmonary Rehabilitation
Program, Royal Prince
Alfred Hospital*

Some of Alice's outstanding qualities are her organisational skills. She has organised World COPD Day walks and activities, Support Group newsletters, and managed the Group's budgets and accounts. She also has a talent for making up hamper baskets for raffles. We thank you Alice for all your hard work over the years and the support you have provided to other patients living through difficult times.

Seminar Report - Keeping Us On The Move - 10th July 2012

Our midyear seminar was held at the Northcott Centre and was attended by some 50 members. Three guest speakers presented interesting and sometimes amusing topics and all seemed to enjoy the day of learning, discussion and companionship. As usual a number of people contributed to the organisation of the day and a thank you must go out to Alice Smart, who ran the raffle and provided a lovely morning tea, to George Laszuk who ordered a scrumptious lunch and dealt with many last minute tasks, the office staff who handled registrations, John Tierney who was our master of ceremonies extraordinaire and Merle Thompson our 'gracious giver of gifts' to the presenters. A thank you also to all those members who made the effort in the cold winter months to make the trip and attend a whole day event when we can all appreciate how limited our energy can be. I think all will say it was well worth it as we enjoyed catching up with other likeminded friends.

Dr Stiofan MacSuibhne is Policy and Development Officer for the Australian Osteopathic Association and practices as an osteopath part-time in Sydney. He has a degree in Molecular Biology (Uni. London) and worked as a clinical scientist. He qualified in 2001 at the London School of Osteopathy and taught for several years at both the British and London schools of osteopathy. He was chair of the New Zealand Osteopathic regulatory body from 2008-2011 and is currently completing a master's degree in health science with a focus on rehabilitation/gerontology at AUT University Auckland. Clinically he has a particular interest in chronic pain and the older patient age group.

John Tierney introduced Stiofan to our members and gave a brief insight into his experience with osteopathy. John attends his osteopath fortnightly and, along with hydrotherapy, accredits this treatment with keeping him moving.

Stiofan stated that the Australian Osteopathic Association has 80% of the Australian profession as members and offers continuing training and education to them. To find an osteopath that is local to your area visit their website: <www.osteopathy.org.au> or Phone: 9410 0099. Osteopathy is covered by most private health funds and the Medicare Enhanced Primary Care Scheme. (see P2 of this Newsletter).

Osteopathy originated in America and was founded by Dr Andrew Taylor in 1874. He had been a field surgeon in the American Civil War of 1861 and later experienced the death of his children of meningitis in 1864. These life experiences and his grief resulted in his disillusionment with medicine and him abandoning the practice of medicine. Medicine was often brutal and ineffective. He searched for a more humane form of medicine, a system of healing – applied anatomy and drug free. In 1894 the American School of Osteopathy was founded. American osteopaths are fully licensed Medical Surgeons. This new school of medical thought was conceived as a reformation or improvement of conventional medicine, not an alternative system.

Osteopathy was introduced into Victoria, Australia by Florence McGeorge in 1904. In 1940 British Osteopaths started to arrive in Australia and started private colleges for training of osteopaths. RMIT university courses commenced in 1986 and there are currently three universities training osteopaths in Australia. It is a 5 year full time degree and 150 osteopaths graduate per year. Osteopathy is a regulated health profession in all states.

Osteopathy is best known for its holistic approach; mind, body and spirit; and for its techniques. Osteopathy is a hands-on approach to healthcare recognising the important link between the structures of your body and the way it works. Osteopaths focus on how your skeleton, joints, muscles, nerves and circulation work together to improve your health and well-being.

Osteopathy is 'new' but not really. In 400BC texts describe joint mobilisation as a standard part of medical care. It was known as 'bone setting' in Europe. Joint mobilisation and physical therapy with an aim to restore general health has been an integral part of traditional healing systems in many cultures.

Using skilled evaluation, diagnosis and a wide range of hands-on techniques, osteopaths can identify important types of dysfunction in your body. Osteopathic treatment uses techniques such as stretching and massage for general treatment of the soft tissues (muscles, tendons and ligaments) along with mobilisation of specific joints and soft tissues.

Osteopaths treat many conditions such as sprains/strains, chronic disease management, pain, arthritis, headache. They offer self-management strategies and give advice on ergonomics and promote health.

In Australia, osteopaths are university trained in anatomy, physiology, pathology, general medical diagnosis and osteopathic techniques. Osteopaths are primary healthcare/allied healthcare practitioners and are trained to recognise conditions which require medical referral. They are also trained to perform standard medical examinations of the musculoskeletal, cardiovascular, respiratory and nervous systems.



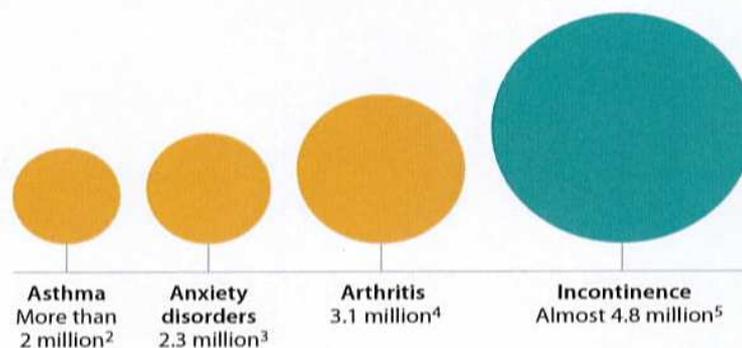
Barbara Scales is the Continence Nurse Advisor as well as Health Promotion Officer for the Continence Foundation of Australia in NSW. As part of the "Continence Outreach Program" Barbara provides a clinical service for people who meet the HACC criteria and who experience bladder and bowel control problems. This involves her visiting people in their own homes as well as conducting a clinic at the Hawkesbury Community Health Centre.

www.continence.org.au and www.bladderbowel.gov.au Helpline Freecall **1800 33 00 66**

This topic can be an awkward and embarrassing to talk about but Barbara was able to put us all at ease with a few funny stories and was able to present to us explanations and advice to suit our audience. It was very informative and sometimes amusing.

In 2010 nearly **4.8 million Australians** aged 15 years and over were living with urinary incontinence. One million Australians have faecal incontinence. Only 50% of people seek help. 70% of people with continence problems may improve with simple lifestyle changes. Experiencing incontinence is never normal, there is always a cause and there are treatment options available. It affects people socially, emotionally, physically, psychologically and economically. Barbara encouraged people to contact CFA for help and advice 1800 33 00 66.

Prevalence compared with other chronic conditions



Incontinence is accidental or involuntary leakage of urine from the bladder or faeces from the bowel. It is a symptom NOT a disease. Types of urinary continence issues:-

- Stress incontinence (coughing, sneezing)
- Urge incontinence
- Mixed urinary incontinence (frequency with urge)
- Nocturnal Enuresis (bed wetting)
- Over Active Bladder (Urge and frequency with no leakage)
- Continuous Urinary incontinence
- Nocturia (waking more than 4 times to toilet at night)

What is normal bladder function:-

- Good steady stream that takes one minute at the most
- Urinating between 4-7 times in the day or once/twice at night (unless you are elderly)
- Hold approximately 300mls of urine in the bladder with no sense of urgency
- No blood in urine
- No pain
- No straining
- No leakage – no matter how small

Causes of bladder incontinence:-

- **Constipation**, causing pressure on bladder
- Diarrhea
- Chronic coughing
- Childbirth
- **Dexterity**
- Irritable bowel syndrome
- **Diet** low in fibre
- Poor **fluid intake**
- Toileting habits (waiting too long between toilet stops)
- **Medications** eg. Fluid tablets
- **Changes in mobility**, taking too long to get to toilet
- Psychological conditions
- Neurological disease and cognitive changes
- **Pelvic Floor Muscle weakness**
- Congenital birth conditions

What is normal bowel function:-

Anything between 3 bowel motions per day to 3 bowel motions per week.

Poor bowel control can be caused by constipation, functional and mobility limitations, neurological conditions or disease eg Parkinson, diabetes; damage to anal muscles due to child birth; surgery eg prostate removal; treatments eg radiotherapy or chemotherapy. All of these issues can lead to weakening of the pelvic floor and anal sphincter muscle which diminishes your ability to 'hold on' resulting in faecal incontinence.

Management and Treatment Options:-

- Maintaining healthy fluid (6-8 glasses) and diet intake (5 veg / 2 fruit)
- Review of medication that can contribute to incontinence
- Ensure toilet is easily accessible and available
- Consider aids e.g. wall rails, raising toilet seat, continence aids (clothing, pads, bedding & chair protection, lifting equipment if required)
- Toilet timing strategies (pace yourself to avoid urgency)
- Pelvic floor exercises (prescribed by a physio or continence nurse)

- **NATIONAL CONTINENCE HELPLINE 1800 33 00 66**
- Websites: **www.continence.org.au** and **www.bladderbowel.gov.au**
- GENERAL PRACTITIONER
- SPECIALIST DOCTOR e.g. Urologist, gastroenterologist, colorectal doctor
- PELVIC FLOOR SPECIALIST e.g. Physiotherapist
- CONTINENCE NURSE ADVISOR
- COMMUNITY HEALTH CENTRE
- **NSW CFA Branch PH: 02 8741 5699**

There are many pamphlets, leaflets and fact sheets available from CFA at the above contacts.

Financial assistance can be obtained through:

EnableNSW – Program of Aids for Disabled People: **www.enableNSW.gov.au** or **1800 362 253**

CAPS – Continence Aids Payment Scheme (Australia-wide)
www.bladderbowel.gov.au or **132 011 option 1**

For the National Public Toilet Map go to **www.toiletmap.gov.au**



Gail Le Bransky is the Manager, Disability Access, with Transport for NSW and has over twenty years experience on social inclusion issues. Ms Le Bransky has the responsibility for guiding the implementation of initiatives to improve access to transport services for all customers. This includes planning for accessible infrastructure, improving customer service for people with disabilities and older people, and ensuring that people with disabilities are part of the Transport for NSW workforce.

Prior to joining Transport for NSW in August, 2012, Gail was Director of GML Social Research. GML Social Research was established in 2003 as social policy research and planning consultancy. Over 8 years, Gail worked extensively with the NSW Government and local councils in NSW on policy and planning issues relating to disability, including the development of Disability Action Planning guidelines for all NSW Government agencies.

Gail outlined what is meant by accessible transport and the expected demand for it in the future. Transport must be accessible to all customers including the physically disabled, the deaf or blind, older people with less mobility, parents with prams, business people and travellers with luggage. Transport for NSW has a legal obligation under the Disability Discrimination Act and associated Standards to provide accessible transport. Accessibility enables social inclusion by providing access to employment, education services, contributing to individual and community wellbeing, improving health outcomes and increasing quality of life.

The key elements to accessible transport are step free access, reliable information on each service to plan journeys effectively, information and signage during the journey in a variety of formats, and above all staff who are trained to be aware of and responsive to the needs of all customers.

Gail pointed out that some taxpayers might wonder why so much should be spent on upgrading our transport system. However, statistics shows that approximately 19 per cent or 1.33 million people in NSW have some form of disability of which 423,000 have a profound or severe disability, half of whom are aged over 65. These numbers will only increase in the future as “baby boomers” age.



Transport for NSW's vision is for barrier free access through universal design principles or providing equivalent access when this is not possible e.g. use of boarding ramps on trains. This is a difficult and highly expensive task when dealing with a railway network that began over 100 years ago. To date 131 stations (42.7%) on the City Rail network have 'easy access' for wheelchairs, compared to 96 in 2007. Currently upgrades are underway at Sydenham and Windsor with a further 11 stations announced for upgrades around NSW. 69% of STA bus fleet is wheelchair accessible. Funding has been provided to private bus operators throughout NSW to improve their compliance with disability standards. Local councils are responsible for providing accessible bus stops and have a deadline to improve these.

Gail stated that even though Transport NSW will continue to focus on technical compliance to standards, more emphasis will be made to improve outcomes for customers with disabilities eg by accelerating installation of ramps at stations. It will talk and listen more to people with disabilities and older people and design accessible transport services to meet customer needs. Performance will be measured against customer's satisfaction with safety, comfort and ease of boarding transport services.

A Disability Action Plan for 2012-2017 will be released in December 2012. It will cover increasing accessibility of the transport network; improving the journey experience of customers through improved information, comfort and services; engaging with people with disability to understand what they want from our services, and receive their constructive feedback; partnering with local governments and other areas of government to ensure that there are no unnecessary barriers; and providing additional employment opportunities for people with disabilities.

Pat Featherstone related her experience with her local bus group and the use of her three wheeled scooter. Gail stated that these scooters are not considered stable for bus or train journeys and that four wheeled scooters may be too big for train trips due to door sizes.

The issue of disabled toilets being locked was raised, some of these are fitted with Master Locksmith Access Key (MLAK). Keys can be purchased by those eligible. Ph 1800 810 698.

Gail addressed a number of other questions from the audience and was interested in our experiences and comments. It is this feedback that will help to assess if staff training is successful and needs are met.

For information on Transport NSW including planning a trip: www.131500.com.au or Ph: 131 500. Gail also supplied copies of a booklet: "Accessing CityRail – Your guide to accessible services"

Our fourth speaker was **George Laszuk** who is a Polio NSW member and our Office Co-ordinator. George has extensive experience with Transport NSW and its services.

George is well known in our polio community but for those who don't know George, he is hard to miss!! He gets around at an alarming rate in his XL electric wheelchair with various attachments included.

George stated that if it had been 10 years ago or even 5 years ago he would not have been able to get around using the transport system as he does today. George travels to Northcott 3 or 4 times a week by bus, train and then bus and has found all the accessibility and assistance needed to make the journey possible. George praised the transport system as it is today and has found the staff to be very helpful providing ramps from the platform to the train when necessary.

George has also travelled extensively on country trips including a trip to Melbourne last year to the Polio Health and Wellness Retreat. He said that there are benefits when travelling on country trips

in that even though you have a standard ticket you need to be put into the first class section so his wheelchair can be accommodated!

Gail stayed through this presentation from George and appreciated the comments made and asked questions and made comments herself. She felt that there will always be areas that cannot be accessible due to the age of the railway system and the general terrain of Sydney.

Merle thanked each of our guest speakers for attending our seminar and presented them with a gift of appreciation.

Gillian Thomas drew the numbers for the raffle and the lucky winners were Joy Willis and Elizabeth Woods, both ladies attend the Hills District Support Group.



Stop Press: Speaker booked for AGM, 17 November 2012

We are excited to announce that we have been able to entice a presenter from this year's Sunshine Coast Polio Health and Wellness Retreat to speak at our AGM. Dr Peter Nolan is a General Physician at Toowoomba Hospital, Queensland, as well as a Clinical Associate Professor of Medicine at the Rural Clinical School, University of Queensland.

He has been working with polio survivors for a number of years and has a particular interest in respiratory problems in the post polio community.

The topics of his presentations will be announced in our next newsletter.

This will be a 'not to be missed' seminar so put the date in your diary now!!



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

About Polio NSW

The Post-Polio Network (NSW) Inc was formed in 1989 by polio survivors for polio survivors. In 2011 the Network changed its name to Polio NSW Inc but our services for polio survivors remain unchanged.

Polio NSW is a self-help, self-funded organisation governed entirely by volunteers. Polio NSW provides information about polio's late effects and supports those who may be affected now or in the future. We conduct regular Seminars and Conferences, publish *Network News*, foster the establishment of regional Support Groups throughout NSW and the ACT, and maintain a comprehensive website.

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

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 Polio NSW's income, which is used to provide its services, comes from membership subscriptions and donations.

Resources for Members

On joining Polio NSW, 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.

Polio NSW also stocks various publications which further describe the late effects of polio and their management. The prices quoted below are for members and postage is included. To order, just write to us – please make cheques / money orders payable to Polio 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>
Polio NSW has for sale a 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 Polio NSW. Not only is the badge a great fashion statement, it is an innovative way to promote Polio NSW.	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 Office.