



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 the second combined Polio NSW and Polio Australia newsletter. Each quarter your copy of *Network News Incorporating Polio Oz News* will bring you regional, NSW and Australia-wide content, together with overseas material of interest. Space for your articles, letters and stories will always be available.

With this issue I am hanging up my Editor's hat. Over the last couple of years I have found it increasingly difficult to give the time to the preparation of the newsletter that it, and you, deserve. It has been an enormous privilege to be the Editor for 80 issues of *Network News*, but with Issue 81 I am leaving you in good hands – past-President Nola Buck (who has re-joined the Committee) and new Committee member Susan Ellis have taken on the challenge of bringing you a comprehensive and informative newsletter each quarter.

Members will recall that on 26 November 2011 the Network held a Special General Meeting before our 23rd Annual General Meeting, to consider changes to the Constitution. The most significant proposed amendment was for the Network to change its name to "Polio NSW Inc". Arguments for and against each proposed change were provided to members and I am pleased to report that all amendments were adopted. The change in name has generated a myriad of related tasks which we are working our way through. Thank you to those who participated in the Special and Annual General Meetings and to those who took the time to submit their proxy.

At the Annual General Meeting the following members were elected to the Management Committee:

Gillian Thomas	<i>President</i>	Nola Buck
John Tierney	<i>Vice-President</i>	Susan Ellis
Merle Thompson	<i>Secretary</i>	Peter Frame
Alan Cameron	<i>Treasurer</i>	Ron Goodwin
Charles Anderson		Bill McKee
Anne Buchanan		Alice Smart

We were delighted with the support shown by members which enabled all 12 positions to be filled. After giving sterling service on the Committee since 2003 we were very sorry to lose the services of our valued Secretary and Support Group Co-ordinator, Neil von Schill, who has experienced considerable ill health since last August. After several small strokes, Neil was affected by a severe stroke in November which cruelly affected his "good" limbs. After several months in hospital Neil is now back home and continuing his rehabilitation. We wish him all the best as he continues to recover. As well as those members who re-stood for a further term, we were pleased to welcome Anne and Nola back to the Committee after some years away. They were joined by first timers Charles, Susan and Peter. Unfortunately, ill health has since precluded both Bill and Peter from taking their seats on the Committee and we wish them better health in the months ahead. Bill provided dedicated service as our Webmaster since 2004 and we give our heartfelt thanks for his endeavours to keep members informed – his talents will be sorely missed. Barbara and Gary Fuller have generously put themselves forward to assist the Committee and will fill the two casual vacancies.

Please turn to page 2 for full details of our upcoming Seminar being held in Parramatta on 10 July 2012. You won't want to miss this great line up so be sure to complete and return the enclosed Registration Form as soon as possible.

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One-Day Seminar - Keeping Us On The Move

Date: Tuesday, 10 July 2012

Time: 9:30 am – 3:00 pm

Venue: Conference Room, Ground Floor, The Northcott Building
1 Fennell Street, North Parramatta

A special arrangement has been made to enable members and friends attending the Seminar to park in the Parramatta Leagues Club car park, thanks to the generosity of the Club management. Simply tell the security person at the car park entrance in Grose Street that you are attending the Post-Polio Network Seminar in the Northcott Building, and please park in the right-hand back corner of the car park. You can then enter the Northcott Building via the gate into its adjacent playground.

Refreshments: Morning tea and a light lunch will be provided (*cost subsidised by PPN*)

Cost: \$10 per person – ***please RSVP by Friday 6 July 2012***

If possible, please return the **enclosed Registration Form** with your payment to the PPN Office by 6 July. Otherwise, you can pay when you arrive at the Seminar, however, if you elect to do this, you **MUST** still contact the Office [*Email office@polionsw.org.au or Phone 02 9890 0946*] by Friday 6 July to confirm your attendance so sufficient catering can be arranged.

Program:	9:30	Registration
	10:00	Dr Stiofan MacSuibhne – <i>Osteopaths: Mobilising Our Bodies</i>
	11:00	Morning Tea
	11:30	Barbara Scales – <i>Continence Advice for Polio Survivors</i>
	12:30	Lunch
	1:30	Gail Le Bransky – <i>Accessible Public Transport: Today and Tomorrow</i>
	2:30	George Laszuk – <i>My Public Transport Experiences</i>
	3:00	Close

Dr Stiofan MacSuibhne: Stiofan is Policy and Development Officer for the Australian Osteopathic Association and practices as an osteopath in Sydney. He qualified in 2001 at the London School of Osteopathy and taught 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.

Barbara Scales: Barbara is the Continence Nurse Advisor as well as Health Promotion Officer for the Continence Foundation of Australia in NSW. Her presentation will cover what CFA services provide, what continence is, an overview of types of incontinence, healthy bladder and bowel strategies, continence funding schemes available and where people can get help. *'Over 3.8 million men and women experience bladder control problems which can be managed, controlled and even cured.'*

Gail Le Bransky: Gail is the Manager, Disability Access, with Transport for NSW and has over twenty years' experience on social inclusion issues. Gail has 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.

George Laszuk: George is a member and Office Co-ordinator of Polio NSW. He will share with us his experience with public transport.

All are welcome – we look forward to catching up with everyone on 10 July

National Disability Insurance Scheme (NDIS) - Update

The information below was sourced from the NDIS website – see www.ndis.org.au for further information.

In August 2011, the Productivity Commission released a report of the public enquiry into Disability Care and Support.

The Productivity Commission found that the cost of supporting people with a disability represents a very large unfunded liability that must be met directly by government or indirectly by families.

The number of people with a disability is expected to increase significantly in the next fifteen years. At the same time, the number of people able to provide unpaid care will fall. The resulting increase in costs has the potential to overwhelm state treasuries. If current growth continues, the spend on disability services will double in fourteen years. A National Disability Insurance Scheme will ensure governments have the ability to meet current and future needs, whatever the economic climate.

It will also provide other important economic benefits. By focusing on early intervention and identifying those supports and services which are the most effective and efficient, the scheme will maximise potential and facilitate greater independence. By providing people with what they need, when they need it, the scheme will ensure people with a disability have every opportunity to reach their full potential.

Providing people with a disability with what they need, when they need it, should also reduce the responsibility currently borne by families and enable them to more fully participate in the economy and the community.

The scheme would be funded by all taxpayers through general revenue. Funding for essential care, support, therapy, aids, equipment and training would then be drawn from this pool of funds.

The principal beneficiaries would be those people with a disability. Most importantly, the scheme would provide support no matter how that disability was acquired. People born with a disability or who acquire a disability through accident, injury or medical condition would all be eligible for assistance.

Eligibility for the scheme would be transparent and based on careful assessment. The system would be person-centred and individualised, based on the choices of the person with a disability and their family. The system would focus on early intervention and providing those supports which produce the best long term outcomes. It would maximise opportunities for participation and productivity. The system would be fair, efficient and equitable.

There are difficult issues which must be confronted before the scheme can be introduced, such as eligibility criteria and levels of benefit. The interface between the disability, aged and health care sectors must also be assessed.

On the 30th April 2012, rallies were held in all capital cities of Australia at which Members of Parliament of both the Government and Opposition were present. At the Sydney Rally the Prime Minister announced that in the May Budget the Government had allocated their share of funds for the National Disability Scheme. From the middle of next year, selected launch sites will begin serving 10,000 people with a disability.

The NDIS will make a huge difference to most people with a disability, but to many people who contracted polio in the early epidemics they will be ineligible because they will come under Ageing Funding. However, for our children and grandchildren, who have a disability, this Scheme will enable them to “aim for the sky”.



Member Marion Wardman has a kind offer for members.

Marion has donated a pair of near new Size 9 Jackeroo brand boots with calliper hole in right boot. She has also donated some used callipers. If anyone is interested in any of these items please contact the Polio NSW Office.

We were recently contacted by Wayne Woodcroft who is trying to find out if anyone who was a patient at Prince Henry Hospital between 1949 to 1951 might be able to shed some light on his father's time there. If anyone can help Wayne, please contact the Office and we'll put you in touch.

I am trying to find out if there are any surviving people that were at Prince Henry the same time as my late father. His name was George Woodcroft and he was from Lidcombe. He was about 17 to 19 years old and was in hospital from about 1949 to 1951. If anyone has any information that may help me in my search of the "lost" years, I would appreciate hearing from you.

Interstate Taxi Transport Subsidy Scheme (TTSS) Vouchers

As a member of the TTSS, you are eligible to travel interstate and be recognised as a member of the New South Wales Taxi Transport Subsidy Scheme, thereby receiving a subsidised taxi fare in other states. However, regular TTSS travel docketts cannot be used for travel outside NSW.

TTSS participants who will be travelling interstate need to order interstate travel docketts. Interstate travel docketts allow TTSS participants the benefit of the half fare taxi subsidy while visiting other states or territories (up to a maximum subsidy of \$30 per trip).

Important: Generally a minimum of 2 weeks' notice is required when ordering interstate travel docketts so please plan ahead.

Complete the Order Interstate Travel Docketts (pdf 501KB) form, available from this webpage <www.transport.nsw.gov.au/ttss>, and send the completed form to the address provided.

For further information visit the TTSS webpage given above or call the TTSS staff (toll free) on 1800 623 724.



We are delighted to advise members that Polio NSW's Vice President (and National Patron of Polio Australia), Dr John Tierney (photo left), was honoured on Australia Day with a Medal of the Order of Australia "for services to parliament, education and the community".

John's achievements include being a Liberal Senator for New South Wales in the Parliament of Australia from 1991-2005. John says he will never forget a Parliamentary Delegation to New York in 2004. "I actually got to address the whole United Nations in the General assembly", he said. "I would say that's the highlight of my career."

John contracted polio soon after he was born and, although he initially recovered well, he now lives with the late effects of polio. Drawing on his extensive parliamentary experience, John assists both Polio NSW and Polio Australia with pro bono advocacy to inform the NSW and Federal governments about the late effects and our need for appropriate services.

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

The Australian Polio Register was established by Polio Australia in October 2010 to gather information on the numbers of polio survivors living in Australia today, whether or not they contracted polio in this country. There are currently more than 1,700 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.



2012 Polio NSW Seminar Program

Tuesday 10 July 2012	Northcott Building 1 Fennell Street Parramatta	Mid-Year Seminar Dr Stiofan MacSuibhne – Presentation Title Barbara Scales – Presentation Title Gail Le Bransky – Presentation Title George Laszuk – My public transport experience <i>Full details are on page 2, Registration Form enclosed</i>
Saturday 17 November 2012	Burwood RSL Club 96 Shaftesbury Road Burwood	Annual General Meeting and Seminar <i>Further details will appear in the next Network News</i>

Management Committee - Executive Members Contact Details

Gillian Thomas	President	president@polionsw.org.au	02 9663 2402
John Tierney	Vice-President	vicepres@polionsw.org.au	0417 277 908
Merle Thompson	Secretary	secretary@polionsw.org.au	02 4758 6637
Alan Cameron	Treasurer	treasurer@polionsw.org.au	0407 404 641
Committee Members (for contact details please ring or email the Network Office): Charles Anderson, Anne Buchanan, Nola Buck, Susan Ellis, Barbara Fuller, Gary Fuller, Ron Goodwin and Alice Smart			

PPN Office and Other Contact Details

Office staff: George, Carlie and Fatma		office@polionsw.org.au	02 9890 0946
Volunteers: Nola, John and Shylie			
Susan Ellis	Seminar Co-ordinator	seminar@polionsw.org.au	02 9487 3094
<i>Position Vacant</i>	Website Webmaster	webmaster@polionsw.org.au	---
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.