



# POST - POLIO NETWORK (NSW) INC.

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## NETWORK NEWS

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**Patron: Professor Emeritus Sir Gustav Nossal AC CBE FAA FRS**

### President's Corner

Gillian Thomas

Our Mini-Conference on 16 December was an outstanding success, with nearly 100 members and friends in attendance. Rehabilitation Consultant Dr Stephen de Graaff's talks demonstrated his depth of experience diagnosing and treating post-polio problems, and also revealed his very caring nature. A report on Dr de Graaff's informative presentations will appear in the next issue of *Network News*.

If you attended the Mini-Conference and forgot to pick up your copy of *Network News* (Issue 51) and the *Information Bulletin* (Issue 27), please let Alice know on (02) 9747 4694 and we will post them out with the next Newsletter. Members will find the Network's 2000/2001 Annual Report enclosed with this issue.

At the Network's thirteenth Annual General Meeting, which was held immediately after the Mini-Conference concluded, the following members were elected to the Management Committee:

Gillian Thomas	<i>President / Newsletter Editor</i>
Merle Thompson	<i>Vice-President</i>
Alice Smart	<i>Secretary</i>
Peter Preneas	<i>Treasurer</i>
Anne Buchanan	<i>Publicity Officer / Information Bulletin Co-Compiler</i>
Elizabeth Joyner	<i>Committee Member</i>
George Laszuk	<i>Committee Member</i>
Bing Mak	<i>Committee Member</i>
Janet Malone	<i>Public Officer</i>
Bob Tonazzi	<i>Committee Member</i>
John Ward	<i>Committee Member</i>
Mary Westbrook	<i>Seminar Program Co-ordinator</i>

Anne O'Halloran did not re-stand for the Committee and our heartfelt thanks go to her for the contribution she has made in the areas of funding submissions and advocacy over the last three years. While not elected to the Management Committee, Allan Quirk and Neil von Schill will assist the Committee as advisers on access and regional issues respectively. Neil will also continue in the vital role of Support Group Co-ordinator.

Our volunteers are the backbone of the Network – without their dedication and commitment the Network would cease to exist. Therefore, at the conclusion of the AGM, we held a special ceremony to celebrate the Network's volunteers and publicly demonstrate our appreciation for their work. Seventy official *International Year of Volunteers* Certificates and Lapel Badges were awarded to members and friends who have unstintingly and unselfishly contributed their time and talents to the Network over many years. Congratulations to all who received this well-deserved award.

Our first Seminar for 2002 will be held on Saturday, 2 March - see the enclosed flyer for full details.

Finally, as I write, New South Wales is being devastated by bushfires. Members in the fire-affected areas are in our thoughts, and we sincerely hope that no losses have been sustained.

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## Visit by Post-Polio Network Friends to “Canaan of God's Comfort” Theresa Park on 17 November 2001

*Roving Reporter Sister Diadema sent this report on our trip to her home which we visited as a Post-Polio Awareness Week social activity.*

What joy to wake up to a brilliant, blue-sky day with hardly a breath of wind! I rose early in eager anticipation of my guests' arrival later in the morning. My Sisters helped with the preparations - sweeping the picnic gazebo, setting out enough chairs, putting out the hot water urn, cups, tea, coffee, cold drinks and so on. What would my guests be interested in as a little souvenir of the day? - ahh - our postcards with beautiful scenic panoramas and an encouraging verse. Everything was ready.

The first car arrived! “Are we in the right place?” “Yes, you certainly are! Please come and relax in the shade until the others arrive.”

More cars - a leisurely hour goes by - and then, at last, the bus! Post-Polio Network members tumble out, relieved to have reached their destination at last, after delays due to mechanical failure of the back door! Is that Gillian wedged in the back? Yes!

An informal time of lunch and getting-to-know-you followed, and I strangely feel as if I have known these people for many years - we just seem to “click”!

Time for a tour. First, the little historic chapel, which is cool and refreshing in the hottest part of the day. My Sister who plays the violin joins us and we give a recital of classical music by Handel, her on the violin and me on the Hammond organ. It is, as always, such a pleasure to make music.

The tour continues at a leisurely pace, but the afternoon is going fast. A look at the printshop, the prayer garden and a circuit of the grounds including the fountain follows.

Then it's time for afternoon tea, a group photo or two - or was it five? - and then everyone gathers belongings and heads for the cars and the bus. How quickly the hours sped by, and my Sisters and I stood and waved farewell - not forgetting to sing our “Goodbye Song”, of course.

Thank you, Gillian, for organizing the group, and thank you to all who came to visit. The weeks have flown by and it is now a pleasant memory - but one that I hope will be repeated some time in the future.



Photo: Courtesy Carmelita Bongco

Some of the Network members and friends who joined Sister Diadema (front, second from left) at her home. Everyone enjoyed a leisurely day chatting and strolling through the grounds.

## Professor Richard Jones Retires

On 8 November 2001 I was privileged to be invited to say farewell to Professor Richard Jones, who retired from the Prince Henry Hospital after a career spanning 38 years. The farewell was held in the Prince Henry Canteen, overlooking the ocean – just one of the tranquil spots for which Prince Henry is renowned and which will soon be lost when the Hospital is closed.

Dr Stella Engel, Director of Rehabilitation and Spinal Medicine at the Hospital, noted in her farewell speech, “Professor Richard Jones is one of the pioneers of rehabilitation medicine in NSW. As well as teaching and helping to build state-of-the-art services at the Prince Henry Hospital for people with spinal cord injuries, those with neurological disorders, and amputees, he was one of the founding fathers of the College of Rehabilitation Medicine.”

In December 1968, Professor Jones was appointed by the Prince Henry Board of Directors as a Specialist in Rehabilitation Medicine. The need for a Rehabilitation Unit at Prince Henry had become apparent in 1961 due to the severe polio epidemic of that year with 133 patients admitted with paralytic polio, many of whom were severely physically impaired and clearly needing extended rehabilitation.

From his early involvement with polio patients, Professor Jones maintained a life-time interest in polio and its often devastating after-effects. He has been a strong supporter of the Network and its activities since our foundation, and in the early 1990s was the driving force behind the establishment of a Post-Polio Clinic at the Hospital.

In his speech in reply, Professor Jones kept us entertained with anecdotes drawn from his time at Prince Henry, including stories of people and events from the polio days.

The Professor’s reminiscences were surprisingly interrupted when, glancing out of the picture windows of the Canteen, he suddenly shouted “There’s a whale!” Everyone rushed to look, the farewell momentarily forgotten. As the whale cavorted in front of us for several minutes it was as if it, too, was saying goodbye to Professor Jones.

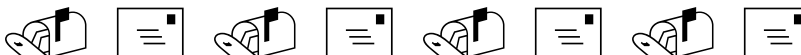


President Gillian Thomas congratulates Professor Jones on his retirement, and presents him with a gift as a reminder of our friendship.

Professor Jones later wrote to the Network: “My dear friends, I will NOT forget you. Your courage and dedication has been an inspiration to me both personally and professionally.

Thank you for your best wishes and the kind gift. I wish you all the best possible health. Stick with it! If I can help, let me know.”

# Post-Polio Post



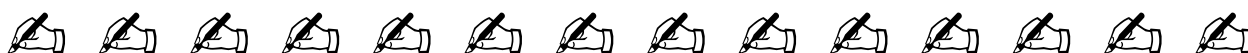
Another regular contributor to Post-Polio Post is member Ruth Crowder of Nambucca Heads. Ruth has answered Ian McKenzie's call for members to tell of their experiences as they age with polio and identify the need for more suitable accommodation options. I hope Ruth's letter is the first of many we receive on this subject – we can all learn so much from each other, but first we have to share.

I found Ian McKenzie's letter on the back page of your October Newsletter [*Network News*, Issue 50] helpful and encouraging.

Making the transition from living independently and working is almost as hard as learning to live with and accept disability. I thank and congratulate him for writing it down so we can share it and learn from it. I think the answer is to make the change when it is your decision and not wait until you are told what you have to do.

I will soon have to make that choice. I can still live on my own in my own home because it is set up for me, and I can manage with Canadian crutches. However, venturing out is now very difficult and I need to use a wheelchair. I still drive my car and have a wheelchair in the boot but I cannot lift it out, cope with gutters, steep slopes or bumpy pavements. The irony is that my overworked arms hurt more than my affected legs. So as Ian says I must face isolation or move on.

I am sure I am very much older than Ian but I do not feel ready for Aged Care. As I am no lover of cooking, prepared meals would be more than a pleasure but passionately I want my own radio channel, music, TV and of course my "space". So, like Ian I will start the search. Thank you for helping me to make up my mind. It is good to know that we are not alone.



## Did You Receive a Form with this Newsletter?

- **If your address label still reads "Renewal Due on 1 July 2001" we have not yet received your membership renewal.** In this case, you will find a Membership Renewal Form enclosed. Please send in your membership subscription as soon as possible. The Network is self-funded and needs your continued support. If you decide not to renew, please tell us why. We need to know if we are not meeting your needs.
- **Raffle Tickets** will be sent to members in early March, with the Raffle to be drawn at our Mini-Conference on 18 May. If you have not yet advised us whether you are willing to buy or sell a few raffle tickets, or make a donation, to help fund Network Conferences and Seminars, you will find a *Raffle Update* form enclosed. If you do not wish to receive raffle tickets, or would prefer to make a tax-deductible donation instead, please complete the form and return it before 22 February.

## Reminder – Coming Events – Dates To Remember

<b>Saturday 2 March</b>	Northcott Centre North Parramatta	Half-day Seminar presented by Dr Elizabeth Ellis <i>Sleep-Disordered Breathing in Polio Survivors</i>
<b>Saturday 18 May</b>	Maroubra Seals Sports Club Maroubra	Full-day Mini-Conference presented by Dr Marcia Falconer <i>Non-Paralytic Polio and Post-Polio Syndrome (PPS)</i> <i>The Polio Virus - Getting to Know Your Old Enemy</i> <i>Some Surprising Facts about Polio and PPS</i>