

POST - POLIO NETWORK (NSW) INC.

NETWORK NEWS

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President's Corner

Gillian Thomas

Welcome to a bonus edition of *Network News* which aims to bring members up-to-date with recent events and remind you of upcoming activities to the end of the year. The bonus issue also allows me to catch up with the backlog of members' letters, and so I have turned over most of the Newsletter over to you.

It has been a busy couple of months. First, our social event *Murder in the Sydney Opera House* on 3 August attracted a disappointingly low, but enthusiastic, number of members, despite perfect weather. Those who did attend were treated to a musical murder mystery in one act in the Agatha Christie short story tradition, written and performed by Barbara Thompson who has appeared with many amateur musical and dramatic societies in Sydney. Barbara's plot kept us guessing to the end. Afternoon tea was as always a great opportunity to catch up with old friends.

Our Seminar on 31 August saw more than 40 members and friends gather to hear guest presenter Adam McLean, Counselling Co-ordinator, Carers NSW, talk about how polio's late effects can influence our relationships. It was a Seminar of relevance not only to polio survivors but also to the important people in their lives and it was pleasing to see family members in attendance.

The Prince Henry Hospital 121st Anniversary celebration held on 7 September was a great success. A thanksgiving service was held in the Coast Chapel in the presence of Her Excellency Professor Marie Bashir AC, Governor of NSW, who unveiled a plaque following the service. We learned that the Governor has a special affinity with the Hospital because she used to visit her two nephews who were patients there in the 1950s, having contracted polio. The Museum, especially its iron lung, proved very popular. We were fortunate that the Network's stand was in a prominent position and attracted a lot of attention. Welcome to the new members who joined as a result of our presence, and thank you to those members and friends who gave up their Saturday to help.

You may be interested to know that over 30% of Network members have access to the Internet. However, very few have so far registered to participate in the new Members' Forum which was announced in the August Member Update. Our volunteers, Webmaster Tony Marturano and his assistant Peter Preneas, put a lot of work into setting up the Forum to allow members easy access to each other's knowledge and experience. Please give them some encouragement by registering today so you can make comments and ask questions – easy-to-follow instructions are on our website. Overseas polio survivors have been thrilled to find the Forum – what are you missing?

There are a lot of activities planned over the next couple of months, as detailed on page 2. The Committee hopes that members will give their support to these activities, and to the Network, where able, and we look forward to catching up with existing and new members alike soon. All familiar items will return in the next issue of *Network News*, including Polio Particles, Support Group News, and feature articles. Look out for *Network News* Issue 56, together with the 2001/2002 Annual Report, in your letterboxes in November.

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Prince Henry Hospital and Beyond – Second Reunion of Polio Patients and Staff : 25 October

Our original Reunion, just two years ago, proved so successful that by popular demand we are doing it again – bigger, better and cheaper! This is the final reminder to anyone wishing to attend the Reunion (Regency Function Centre, Burwood RSL Club, from 10:30 am to 3:00 pm) – your Form and payment are due NOW. The cost of \$25 per person includes tea and coffee on arrival, a buffet lunch and non-alcoholic beverages. Spouses, partners, accompanying persons and friends are most welcome. We will be joined by distinguished guest speaker Professor Richard Jones, one of the pioneers of rehabilitation medicine in NSW. We are delighted to note that at least twelve former nurses from Prince Henry Hospital are expected to attend, and hope to see you there too. If you have misplaced the Form sent out with the August Member Update just get in touch and we will post or email one to you. Contact Gillian on (02) 9663 2402 or email her at gillian@post-polionetwork.org.au.

Post-Polio Awareness Week : 1 – 7 November

Post-Polio Awareness Week is our major publicity effort each year to raise the awareness of polio survivors, health professionals and the general community about the late effects of polio and their impact on our lives and those of our families. The theme for 2002 is ***Every man and his dog should know about post-polio syndrome*** and our colourful poster features member Allan and his assistance dog, Jacko. Again this year we are including a couple of posters with this *Network News* together with copies of our new pamphlet. We ask all members to put the posters up somewhere in your local community and distribute the pamphlets as widely as you can. If you want more supplies, especially of the pamphlets which can be used independently of Post-Polio Awareness Week, just give Alice a call on (02) 9747 4694 or email her at secretary@post-polionetwork.org.au. Finally, if you are willing to talk to local media about your polio story and the work of the Network, please contact Alice for a copy of the Network's Media Release and for any background information desired.

Help Needed for Home Care Training Presentation

In the recent Member Update we reported that the Management Committee will be conducting a training session on 14 November for the Home Care Service at Dee Why. We sought ideas from members about the issues we should raise during this training. It does not matter whether you live in the Dee Why area or whether you currently receive assistance from Home Care – we want to hear from you. We wish to convey to the attendees the issues our members face in personal and home care, whether this is currently provided by families and/or friends or by outside bodies such as Home Care, and whether your concerns are about current or potential future needs. Please help us to help you by providing some input to our presentation. You can ring Gillian on (02) 9663 2402 or Merle on (02) 4758 6637; write to us at the Network, PO Box 888 Kensington 1465; or email Gillian at gillian@post-polionetwork.org.au or Merle at mkthom@bigpond.com.

Annual General Meeting and Seminar : 30 November

Our AGM is fast approaching and the Agenda is enclosed. Please try and come to this important yearly meeting which will be held as usual at the Independent Living Centre, Ryde, starting at 11:00 am. This is your opportunity to not only have a say in the running of the Network, but to offer your time and talents to help achieve the Network's goals.

Don't forget that at the AGM we will be drawing the winner of the financial analysis and plan, valued at \$1,440, donated by the skilled financial planning team at John Cerniauskas Financial Planning Services, Wollongong. To be in the draw, simply write to the Network or email us at gillian@post-polionetwork.org.au by 22 November.

At 1:00 pm, following the AGM, Melbourne Physiotherapist and Network Member Dr Keith Hill will be presenting a Seminar *Falls, Fear of Falling and Activity in Older People with Polio - What can be done to help?* Full details will appear in the next *Network News*.



The first letter out of the mailbag is from member Norm McCarthy, Goulburn. His contribution is very timely considering the “Prince Henry Hospital and Beyond” Reunion to be held on 25 October. We have endeavoured to get some further information for Norm but have had no luck so far. If any other member, or indeed any reader, has memories of Wendy Stuart, perhaps you could drop a line to Editor and fill in some gaps since 1976.

From time-to-time I find articles and comments within *Network News*, contributed by ex “Polios”, which reveal personal feelings and happenings from the past, that must re-ignite a flood of memories both good and bad, to other readers, as they do me. Over the years when this happens and I need to take stock of the balances dealt to me in life because of polio, I invariably turn to a letter written by a very special person that I knew of, but never met, whilst in Prince Henry Hospital during 1952/53. Her name is Wendy Stuart and no doubt some of our female members from “B” block in that era would know her.

Back in 1976 a feature article within a Sydney newspaper caught my eye. It was about Wendy. Her local Rotary Club had become aware that since contracting polio - 25 years prior – she had never had a holiday away from home, primarily because of her reliance on her iron lung. The Club addressed this as a special project and created a lightweight lung, portable enough to make her dream of a holiday at Batemans Bay a reality.

This article prompted me to write to her and the letter enclosed was her response – a letter that conveyed to me an enviable fighting spirit.

Years moved on and I had no further contact with her. Whilst on a trip to Sydney with Charlotte in 1994, we endeavoured to trace Wendy at her Maroubra address without success. We called at the headquarters of AQA near Prince Henry to learn from the longest serving employee present that, whilst they did not know her personally, they were aware that Wendy had passed away a few years before.

Sadly, I never did learn if Wendy Stuart had her holiday in Batemans Bay!

Here is the letter that Wendy wrote to Norm on 4 September 1976

Dear Norm

What a lovely surprise your letter was to me. I really appreciate the time and effort you took to write me, and yes the photos and names certainly revived memories for me. It is so incredible to think that was twenty-five years ago. How the years fly! Of the names you mentioned, I do know what some of them are doing, although I don't personally keep in touch with them. Terry is a high school teacher. Sue married a Doctor. Margaret phoned me last year - after twenty years – she is unmarried and works in an office. Mavis died many years ago and of the others – I just don't know.

About myself, well many things both good and bad have happened to me. Just to recap as briefly as possible. After leaving PHH in 1952 everything was “fine” for about ten years, I didn't even need an iron lung. Then I had a series of respiratory infections which so weakened my lungs and breathing muscles, that I had a serious complete respiratory relapse in 1962, and that put me in an iron lung. I have had to sleep in it every night since. I am still an out-patient of Prince Henry, and they certainly keep an “eagle eye” on me. I have a weight problem which has them puzzled. My weight fluctuates between 3 and 3½ stone and I have built up quite a collection of kidney stones. So you see, there's never a dull moment. I am a complete quadriplegic with use of my right hand. Mum and I moved into this housing commission flat in 1963 and we like it very much. Mum is marvellous and

looks after me by herself. A whole new world opened up for me three years ago when I was appointed a Director of the Australian Quadriplegic Association. I am Public Relations Officer and it's very stimulating to be involved with the AQA. There are eight on the Board and six of us are quadriplegics. I am the only polio, the others are spinal injuries. Our aim is to raise enough money to build a hostel for the severely disabled. We have almost completed our Activity Centre on our land which is quite near Prince Henry, but I'm afraid the hostel will have to wait as money is scarce. We haven't done too badly in nine years. We are only a small association and not to be compared with the larger Paraplegic & Quadriplegic Association. Being a participating member keeps me busy, which is good.

As for my iron lung, it is working perfectly. I am still waiting for the new motor and bellows to be finished before I can even contemplate thinking about a holiday. But I am living in hope that one day it will be a reality and not a dream.

Well Norm, I will bring this to a close for now. Once again thank you for your kindness in writing. I so enjoyed hearing from you.

My best wishes and regards to you and your family. God Bless. Wendy

It is always a delight to hear from regular correspondent Ruth Crowder, member from Nambucca Heads, and not just because she gives positive feedback!

It is with great pleasure that I renew my membership. I congratulate you on the consistent high quality of your Newsletter. It is important for those of us who do not live in Sydney and cannot attend your Seminars and social events to be kept informed through the Newsletter of changes in attitudes, research and advice.

There are not many post polios in small towns to discuss our changing situations with. I think we were advised to accept what had happened, make the necessary adjustments and get on with our lives. This was good but it can be isolating. Thanks to the polio vaccine, hopefully we are "a dying race".

I have attended sitting-down Tai Chi for many years and have found them to be beneficial and pleasant to do.

My best wishes to you and your team.

Member Grahame O'Reilly, High Range, is also a regular correspondent.

I noticed in your last *Information Bulletin* an ad for contoured pillows. I have used one for over 15 years, at the time it was supplied by my chiropractor. We have been involved with chiropractors for some 30 years; at the time he was Canadian where it was widely practised but here they were looked on as witchdoctors. I go on a regular basis of about 8 or 10 weeks for what we call maintenance as I started to have spinal problems from favouring one side for years. It will be 50 years next January since I contracted polio and I can only say that chiropractic works for me and keeps me mobile. I find it healthier than popping pills.

Artist Margaret Greig, member from Londonderry, has a request ...

I have a vehicle and enjoy travelling whenever time permits. My carers are very good but family commitments usually prevent them from accompanying me. Is there anyone out there interested in being a driver/carers? Two carers always come with me to make life easier. If you are interested please give me a ring on (02) 4578 1470 or email me at eugalahs@zip.com.au

Roger Smith, Pialligo, member and Co-Convener of the ACT Support Group, recently gave me a ring and asked whether I would be interested in publishing one of his poems. Well, here it is ... I thought it described me pretty well, how about you?

A Negative Positive Look

© Roger Smith, 9 July 2002

Life's not what it used to be
It's becoming quite a chore
To do the things I used to do
Like I used to do before

Walking is a major task
I really don't get far
It's really quite a comfort
When I can go by car

Sometimes there's lots of aches and pains
They just appear somehow
I didn't seem to have them then
Why have I got them now

When standing up from sitting down
In a comfortable seated position
It takes a lot of grunt and groan
To complete the task of transition

If nature calls most urgently
I really cannot fake it
The thing that then concerns me most
Is whether I'm going to make it

Another thing I've noticed
Is the apparent lack of air
The abundant breath I had before
Has gone I know not where

If someone says we're running late
I think we'd better hurry
Well, I really only have one speed
Which doesn't allow for scurry

To receive a kiss or friendly hug
From a relly or a loved one
I need to cling to the walking frame
Lest I wobble and then fall some

But hang about let's reconstruct
This negative way of thinking
And return it to the positive
Before I keep on sinking

For polios are a stubborn lot
Who never like to give in
Where there's a will we'll find a way
And always try to win

There is a simple philosophy
Enthusiasm we mustn't sever
That we'll keep going as long as we can
And try to live forever

Member Dr Shelley Phillips, Kirribilli, gives us some insights into the positive steps she is taking to maintain her independence despite an increasing loss of mobility.

In the past my dentist and my doctor have commented on how I'm losing my mobility. I read in the post polio Newsletter the importance of using every aid possible to keep people mobile who developed post polio syndrome, so one of my first acts was to buy a stick. That served well for a while until I fell over after getting out of my car onto a rough patch in the Milson's Point shopping centre. That impressed upon me the importance of putting pressure on local councils to keep their footpaths safe for the disabled.

At my request the local chemist helped with the next stage of keeping me mobile, by purchasing for me and delivering to my door a mobile walking frame with wheels, brakes, a basket and a tray. I can use this to get my rubbish to the disposal chute at the end of the second floor balcony onto which my front door opens. I can also use it to get to the garage in the basement of my building and get it easily into my car there in order to go shopping or for drives with my daughter whenever she comes to Sydney from Auckland or I can go shopping with my granddaughter, aged 20, who comes to help me once a week for a couple of hours. She is a university student and short of cash so I pay her well to augment her pay from several part-time jobs which she does late at night. To help with this I lend her my car.

My latest purchase has been an electric scooter. I am as yet rather nervous of using it because our drive runs straight from the street to the harbour and is practically perpendicular. From the instructions, I gather it is dangerous to drive the scooter up or down an excessively steep incline if the drive is at all wet as it often is in Sydney.

Meanwhile, along with my neighbours who have no car spaces and want garages, I'm negotiating with the managing agent to have garages built at the top of our drive to support a bridge running from our second floor straight to the street. To act as advisors, several qualified people have been engaged and as yet we are not sure it can be done.

As naturally my scooter, although small, is too big, I now find I need in addition to the scooter a very small wheel chair to operate inside and around my unit. If anyone has any ideas please drop a note to shelleyphillips@bigpond.com or write to me care of the Network.

The final letter from the mailbag this issue comes from Marilyn McTaggart, daughter of long-time member Doris Ady, Winmalee. Marilyn wrote to me with the sad news of her mother's death, but also to tell me a bit about her mother's life. When I replied to Marilyn to offer our condolences and to seek permission to publish Doris' inspiring story, I commented how sad it is that we often only learn of the fascinating lives of our members after they have passed away. We who survived polio have all strived and thrived in unique ways. Why not put pen to paper (or fingers to the keyboard) and share your story now?

My mother, Doris Ady, was a member of the PPN for a number of years. She died on 29th July after a hospitalisation of about three weeks.

Network News was a publication Mum looked forward to receiving. She found the practical advice and information it contained to be tremendously helpful.

Having read Judith Plummer's letter about her mother Marjorie Corby, Mum commented to me that all she wanted was to live with us for another ten years (Mum was 81) and enjoy her garden and her dog. Her greatest dread was to be bedridden in a nursing home totally dependent on others. I thank God she was spared that.

Mum contracted polio in 1941 while living in Burma with her parents. She was paralysed from the waist down and told she would never walk again. Nine months later the Japanese were advancing on Rangoon and the order was given by the British Governor to evacuate. Women and children would be flown out – my grandmother refused to go without her husband. So the family joined a convoy and trekked through the jungles of the Naga Hills into India. Mum’s trekking consisted of being carried in a makeshift palanquin by Naga tribesmen and she travelled at the rear of the convoy. The convoy was being led by her friend Tiger Ady. She recalls one morning, as the convoy was moving single file along a jungle track, gunfire was heard. Her porters unceremoniously dropped the palanquin down the side of the track and disappeared into the jungle never to be seen again. She managed to pull herself back up to the track and waited for what seemed like hours, but probably wasn’t, to be rescued.

My parents were married in 1944 and Mum walked down the aisle of the church on her father’s arm! I was born a year later. My earliest memories are of living in Oxford (UK) with my aunt so that Mum could attend the Nuffield Centre for physiotherapy and hydrotherapy treatment of her polio. During this time Dad was back in Rangoon rebuilding his family home to suit Mum’s special needs. My sister was born in Rangoon in 1950 and while young enough to still be in a bassinet was diagnosed with polio in her left arm.

In 1956 Mum talked Dad into selling up and moving to Australia. One problem – the Burmese government would not allow any funds to be transferred. So from a life of colonial luxury and servants, we arrived in Australia with very little money. A friend had offered his weekender at Dee Why – sounded great. The reality – two thirds of the house was rented out, we had one third. No bathroom, no kitchen. And the loo – outside of course at the end of a long backyard! Mum coped magnificently and made it into a huge game for us.

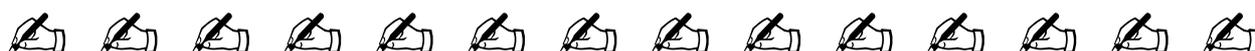
In the next twenty years Mum helped Dad to start up a business importing curries and spices from Asia, she wrote two cookbooks “Curries From The Sultan’s Kitchen” and “Curries From the Burra Bazaar” and opened a retail store “Burra Bazaar” selling curries and spices. When all this got to be too much she retired and came to live with us in a specially designed granny flat. Her body may have been slowing down, but she wasn’t ready to give up. So she took on the job of co-ordinator of the local Neighbour Aid centre!

In the early 90s the first signs of PPS appeared and this meant more adjustments to her way of living and to the granny flat. She invested in a second hand motorised scooter and continued to live as independent a life as she could – a constant inspiration to family and friends alike. Five years ago we moved to the Blue Mountains. In spite of the increasing debilitation of PPS and osteoarthritis, she loved life in the mountains. Her greatest delight was becoming a great grandmother just before Christmas last year. Mum shared a special affinity with a handful of friends, who like her suffered polio in their youth – overcame it and now are coping with PPS. Her legacy is a family of positive people, who are not afraid to face life’s challenges. Thank God for Doris Ady.

As I am not sure of who to contact, I would appreciate if you could advise your membership department of my mother’s death.

A couple of her friends have asked if they can make a donation to Mum’s favourite charity. I think she would like the donations to go to PPN. Please can you email me back and let me know where the donations should be sent.

I would like to thank the team at PPN – your efforts certainly made a difference to the way Mum coped with PPS.



Happy 10th Birthday to the Hunter Area Support Group

Members of the Management Committee travelled north to Toronto on 4 September to join the Hunter Area Support Group as they celebrated their 10th Anniversary. The following account of the day is drawn from the Group's news report prepared by Convener Wendy Chaff. The report, which provides the link that connects Group members, is mailed every two months to some 70 people, of whom about 50 are polio survivors.

Our 10th Anniversary Meeting at the Toronto Workers Club was officially opened at 10:35 am by Chairperson Barbara McCormack, who greeted the 31 people gathered for the occasion. They had come from as far afield as Chain Valley Bay and Branxton, not forgetting the Network's Support Group Co-ordinator, Neil von Schill, who travelled up from Albury. Joining us from Sydney were the Network's President, Gillian Thomas, Peter Garde, and Bob Tonazzi, Network Treasurer. Barbara spoke of our origins and read out portions of the minutes of the first official meeting of our Support Group on 5 August 1992 at Toronto Workers Club, with 28 present. After a great deal of effort and lobbying we were gradually able to gain recognition from Hunter Area Health Service for post-polio problems, and over the years had some of their staff as guest speakers. Barry Chaff reported that during the past 10 years we have been in contact with 140 people who have made enquiries or come along to meetings.



Neil von Schill congratulated the Hunter Area Support Group on achieving ten years of operation. He noted that it was the Network's first Support Group and is still the largest.

After the formal meeting was declared closed, a delicious special luncheon was served and it was time for chatter. President Gillian Thomas then did the honours by cutting the big birthday cake, resplendent with sparklers, to complete the celebrations.

Coming Events At A Glance – Dates To Remember

Friday 25 October	Regency Function Centre Burwood RSL	<i>Social Event - Reunion Luncheon Prince Henry Hospital and Beyond Second Reunion of Polio Patients and Staff Everyone is welcome – RSVPs are needed NOW !</i>
1 – 7 November	Across NSW and the ACT	<i>Post-Polio Awareness Week Please participate if you can – the Network needs your help</i>
Saturday 30 November AGM and Seminar	Independent Living Centre Victoria Road Ryde	<i>Falls, fear of falling and activity in older people with polio: what can be done to help? presented by Dr Keith Hill Senior Research Fellow, National Ageing Research Institute (NARI), and Co-Director, Falls and Balance Clinic, Melbourne Extended Care and Rehabilitation Service</i>