



POST - POLIO NETWORK (NSW) INC.

NETWORK NEWS

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President's Corner

Gillian Thomas

Welcome to the 50th edition of the Network's *Newsletter*. This is a significant milestone for any community organisation to reach, and the Network which operates solely on volunteer labour is very proud to have maintained its *Newsletter* production over 13 years, with the first issue being published in November 1988. The fiftieth issue is a bonus one, to bring members up-to-date with recent events and upcoming activities to the end of the year.

Members who were present at the Seminar held on 22 September learned that the Seminar series to be presented by Dr Halstead in December had become uncertain following the terrorist attacks in America. Dr Halstead lives with his family in Washington, one of the areas most affected. Following the Seminar, I spoke at length with Dr Halstead in America. He confirmed that both he and his wife, Dr Jessica Sheer, were having second thoughts about the air travel required to come to Australia from the east coast of America. They also have a nine-year-old son and were concerned for his safety. Following our conversation, Dr Halstead again discussed the matter with his wife. He later emailed me to advise that their final decision was to cancel their proposed trip. He is very sorry to have let us down but has left the door open for a future visit. We will keep in touch with him to see what may be feasible during the second half of 2002.

Over the last couple of weeks the Committee has been working hard to ensure that the Mini-Conference scheduled for 16 December still goes ahead. We are very pleased to announce that Rehabilitation Consultant Dr Stephen de Graaff, who practices in Melbourne, has accepted our invitation to speak (a profile of Dr de Graaff appears on page 3).

It has also been decided to hold our Annual General Meeting on 16 December (rather than on 15 December as previously advertised). We are honoured that Dr de Graaff will stay with us for the AGM and for our Celebration of Volunteers. The full program for the day is given on page 2. Please support the Mini-Conference and return the Registration Form as soon as possible.

The funding we received from the Department of Family and Community Services' *International Year of Volunteers* grants will assist the Network's Support Group Conveners to attend the Mini-Conference and AGM, as well as giving them the opportunity to meet as a group with the Support Group Co-ordinator, Neil von Schill, and to learn from each other.

With the change of plans for December we've also had to rethink the timing of the raffle, although its purpose as a fund-raiser for future Conferences has not changed. It has been decided to defer the drawing of the raffle until Dr Marcia Falconer from Canada is with us in May 2002. As a result the tickets will now be sent out in February.

There are a lot of activities planned over the next couple of months. 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 features will return in the next issue of *Network News*, including *Polio Particles*; a review of a new book *Post-Polio Syndrome: A Guide for Polio Survivors and their Families* by Julie Silver MD, director of the International Center for Polio in Framingham, Massachusetts; Support Group News; and our feature article on orthotic care for polio survivors. Look out for *Network News*, together with the 2000/2001 Annual Report, in your letterboxes towards the end of November.

Unless otherwise stated, the articles in this Newsletter may be reprinted provided that they are reproduced in full (including any references) and the author, the source and the Post-Polio Network (NSW) Inc are acknowledged in full. Articles may not be edited or summarised without the prior written approval of the Network. The views expressed in this publication are not necessarily those of the Network, and any products, services or treatments described are not necessarily endorsed or recommended by the Network.

Post-Polio Network

Mini-Conference / Annual General Meeting

Date: Sunday, 16 December 2001

Time: 10:00 am - 4:00 pm
Refreshments and a light lunch will be provided

Venue: Regency Function Centre
Burwood RSL Club
96 Shaftesbury Road
Burwood NSW

The venue is readily accessible for those in wheelchairs or with mobility difficulties and there is ample parking. There are lifts from the car park Basements 1 and 2 to the Function Centre on Level 1.

For those catching public transport, the RSL Club is approximately a 180-metre walk from Burwood Railway Station.

Registration: As we have to advise the Function Centre of numbers attending for catering purposes, registration is essential. Please complete the enclosed form and return it as soon as possible. To enable as many people as possible to attend, the Network is subsidising the Mini-Conference and has kept the registration cost to a minimum.

Dr Stephen de Graaff MBBS FAFRM, Consultant Physician in Rehabilitation Medicine, will present the two Keynote Addresses and conduct the Question and Answer Session. See page 3 for a profile of Dr de Graaff.

9:30	<i>Registration and tea/coffee</i>
10:00	Late Onset Effects Of Polio: Are They For Real?
11:00	<i>Morning Tea</i>
11:30	Is Pain Necessary in Polio Survivors?
12:30	<i>Lunch</i>
1:30	Question and Answer Session – You Were Asking? <i>(written questions collected over morning tea and lunch)</i>
2:10	<i>Break</i>
2:15	Annual General Meeting
3:15	<i>Afternoon Tea</i>
3:30	Celebration of Volunteers
4:00	<i>Finish</i>

Dr Stephen de Graaff

Dr De Graaff is a Consultant Physician in Rehabilitation Medicine. He is currently Chief of Rehabilitation Medicine at Cedar Court Healthsouth in Camberwell Victoria, and Head of the Neurological Rehabilitation Unit at Caulfield General Medical Centre. Dr de Graaff is Chairman of the Board of Continuing Education within the Australasian Faculty of Rehabilitation Medicine, past Chairperson of the Victorian Branch of the Australasian Faculty of Rehabilitation Medicine, and member of the Executive of the Australasian Faculty of Rehabilitation Medicine. Dr de Graaff's interests include neurological rehabilitation and musculoskeletal rehabilitation pain management in the areas of stroke, acquired brain injury, multiple sclerosis and polio. Dr de Graaff has a particular interest in combining the neurological and musculoskeletal management of polio survivors.

I Didn't Have Polio - Did I ?

Marcia Falconer, PhD

The gremlins were hard at work in the last Newsletter (Issue 49, August 2001), and unfortunately Dr Marcia Falconer's authorship of the above-named article which appeared on pages 11 to 13 was inadvertently omitted, together with the introductory paragraphs below. My sincere apologies to Dr Falconer for this omission. Don't forget that Marcia will be presenting a number of topics at our one-day Mini-Conference on 18 May 2002.

Regular readers will remember that in Issue 40 of the *Newsletter*, February 1999, we published a paper co-authored by Dr Marcia Falconer, entitled *Non-Paralytic Polio and Post-Polio Syndrome*. When we recently decided to reprint an article by Dr EG Dowsett *The Late Effects of ME – Can They Be Distinguished From The Post-Polio Syndrome?* we asked Marcia if she would write an article especially for us with her viewpoint on the matters raised in Dr Dowsett's article. Marcia readily agreed and soon sent her response, *I Didn't Have Polio – Did I?* When forwarding it, she noted that Dr Dowsett's article is quite scientific, and so Marcia decided to write a more personal, non-scientific article for members. As she said, "I could write a scientific article on enteroviruses, but I thought that might be a bit too much, sort of a double whammy, for the general reader to take in all at once".

Marcia Falconer contracted non-paralytic polio as a child in 1949. She graduated with a BSc in biology from Simmons College, Boston, Massachusetts in 1964, and received post-graduate degrees in plant cell biology (Carleton University, Ottawa, 1985) and neuronal cell biology (University of Ottawa, Ottawa, 1990). Marcia has spent many years researching cell biology, and been published in numerous scientific journals. In 1998 in partnership with other scientists she formed a biotechnology company, BioSoma where she is the scientist in charge of cell biology and animal research. Marcia received a diagnosis of "probable PPS" in 1997 and now works half time. Reprint/publication requests for *I Didn't Have Polio – Did I?* should be directed to: Dr Marcia Falconer, 33 Abingdon Drive, Nepean, Ontario, Canada K2H 7M5, or by email to <ddf@sce.carleton.ca>.

Bowlers on the Central Coast - Correction

Also in *Newsletter* Issue 49, I published an item about bowlers with disabilities who enjoy a social outing and exercise at the Toukley RSL Bowling Club on the fourth Friday of each month (February to November). The bowler in the accompanying photograph was incorrectly stated to be member Brian Nash who helps organise the event. Brian has advised me that he is actually the person handing the bowls to the player in the wheelchair. Brian also tells me that "We have over a hundred bowlers from the Central Coast and up to Swansea that attend this Friday event." If you'd like to join in, please contact Brian on 0412 204 945 for more information.

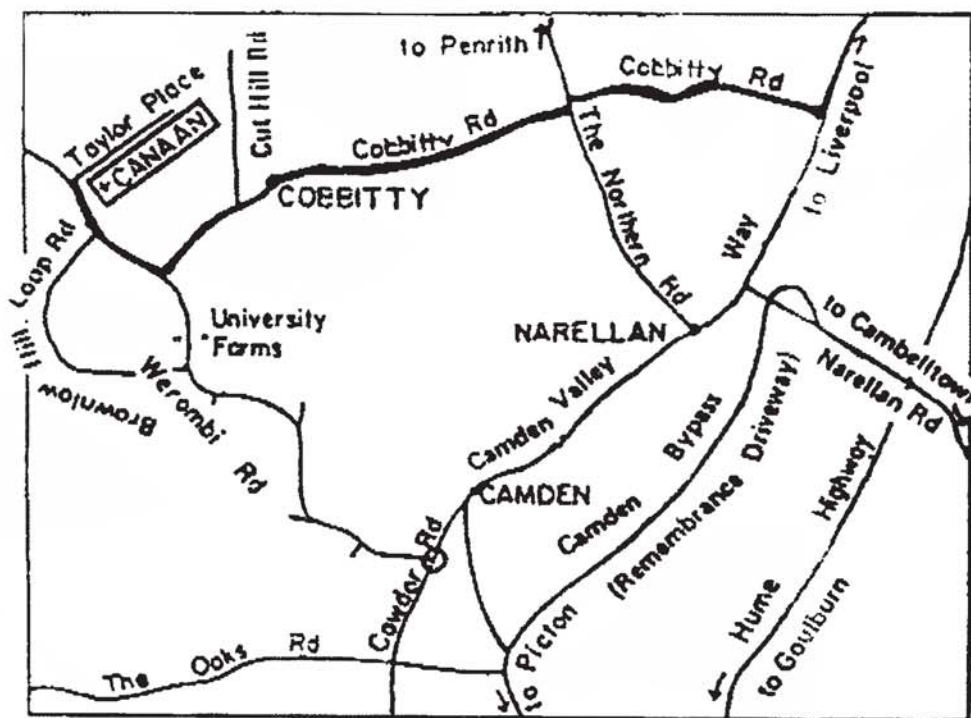
Reminder ! Join us on Saturday 17 November 2001

We are fortunate that the Federal Election will not interfere with our plans to visit the home of the Sisterhood of Mary at 30 Taylor Place, Theresa Park (near Camden) for a picnic and social get-together.

There is plenty of parking at Theresa Park, and there are gentle pathways all around making it very accessible for those with walking difficulties, and for wheelchair users. You should plan to arrive for morning tea (around 10:30 am), and bring your own picnic lunch. Tea, coffee, boiling water, and cold drinks will be provided by the Sisters.

After morning tea Sister Diadema will take us all on a tour of her home, and show us over the print shop, gardens, chapel, and other points of interest. Lunch time is usually leisurely, with free time for wandering around the grounds, or for further questions.

Please join us for this all too rare opportunity to meet with other members in a social setting. To help the Sisters prepare for our visit, please let Alice (02) 9747 4694 know *before 7 November* if you will be coming along. The Committee is hiring an ex-Olympics mini-bus which seats 10 as well as carrying 2 people in their wheelchairs. This will enable some members to join us who would otherwise be unable to attend. As seats are limited, please ring Alice as soon as possible for more information if you would like to travel in the bus.



How to find Canaan of God's Comfort, Evangelical Sisterhood of Mary

If coming from **Liverpool**, take right hand turn after the "Crossroads" and follow the **Camden Valley Way**.

Turn right onto **Cobbitty Road**. At the T-junction turn left onto **The Northern Road** and after approximately 100 mt turn right onto the continuation of **Cobbitty Road**.

Follow Cobbitty Road through the township of Cobbitty and bear left at the traffic island. After the bridge, at T-junction, turn right onto **Werombi Road**.

After 2-3 km, **just before Big Gully Creek Bridge**, turn right into **Taylor Place**. There is a big sign underneath the "Big Gully Creek" sign, saying "Evangelical Sisters of Mary" to ensure you don't miss the turn-off to Taylor Place which is a no-through street, opposite Nectarbrook Stud.)

Australian Foundation For Disabled Celebrates 50 Years

The Australian Foundation For Disabled began as The Poliomyelitis Society in 1952 offering care and support to polio survivors and their families.

The Salk vaccine effectively reduced the numbers of polio cases and the Society opened its doors to encompass people with all types of disability.

Since its beginning in 1952, the Society has undergone many name changes and broadened its service from offering only accommodation, employment and welfare support to include Post-School Option and Day Programs, Training, Recreation Sensory Room and Garden.

Today Australian Foundation For Disabled is responsible for 600 people with disability over an area spread from Newcastle to Richmond.

2002 will mark the 50th Anniversary of the organisation and a number of activities will be held in celebration.

The Foundation is anxious to contact former members or the Poliomyelitis Society, especially those who joined in the 50s, 60s and 70s.

If you were a member, or a friend or a relative of a member, they would be very grateful if you would contact:

Maureen Turner
Fundraising Manager
Australian Foundation For Disabled
PO Box 453
Penrith NSW 2751
Phone: (02) 4777 4250



Support Group News

Neil von Schill

Support Group Co-ordinator

Phone: (02) 6025 6169

Fax: (02) 6025 5194

This is the final call to all members in Sydney's Eastern Suburbs to come along to the Network's public meeting which is aiming to establish a Post-Polio Support Group for the benefit of members in the area. Eastern Suburbs' members have already received personal invitations. Those in the region who have previously enquired about membership but have not yet joined have also been invited. In an attempt to reach polio survivors living in the area who have previously not been aware of the Network, the meeting has also been advertised in the local *Southern Courier* newspaper.

The meeting will be held at South Sydney Junior Rugby League Club, 558A Anzac Parade, Kingsford on Sunday 28 October 2001 commencing at 2:00 pm, and will be followed by afternoon tea (don't forget that daylight saving commences this weekend). Please join us in the Club Auditorium on the second floor which can be reached by lift for people using wheelchairs or those who are less mobile.

Attendees at the meeting will learn about the Network's support group structure, and how participating in a local support group can help polio survivors and their families better understand and manage the late effects of polio. Please help make the meeting a success - register your interest with Alice (02) 9747 4694 TODAY.

The Volunteer Spirit

The Network has recently become a member of www.ourcommunity.com.au which is an Internet website offering many resources to Australia's community and non-profit organisations. An item in their recent Newsletter about volunteers and funding for community organisations struck a chord with me. The following excerpts are provided courtesy of www.ourcommunity.com.au.

In a speech in Melbourne on August 15, the Federal Treasurer, Mr Peter Costello, called on all Australians to get the "volunteer" spirit.

Mr Costello said Government couldn't solve all the country's ills and said it would be a better community if people just got in there and volunteered to help out in their local community groups.

While we applaud Mr Costello's support for the volunteer sector, Ourcommunity.com.au did take issue with the view that volunteers alone could solve all the financial problems faced by non-profit groups.

Here is the media release that we put out in response to the Treasurer's comments:

Ourcommunity calls on Mr Costello to put his money where his mouth is

The Federal Treasurer, Mr Peter Costello, was correct to call for a greater Australian spirit of volunteerism but was way off the mark if he thought volunteer groups could pay their bills and survive on public spirit alone.

"It is great to hear the Treasurer supporting neighbourhood community groups and a greater public involvement but these groups can't do it alone without Government support, no matter if they have one volunteer or 1000", Ms Rhonda Galbally, CEO of ourcommunity.com.au, an online resource for Australia's 700,000 community groups said today.

"It is not always lack of volunteers that holds community groups back. It is lack of money.

"No matter how many volunteers groups have, you still need funding to be able to provide the valuable community services, whether that is putting a sporting team on the field, providing meals or a home for the disadvantaged or running a rural town fair committee.

"The nineties were a disaster for the community sector with Governments of all persuasions cutting back funding to all forms of community groups."

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"Volunteer groups are not just about charity or soup kitchens. They are about setting up a social support system that hopefully prevents people from getting to the stage where they need serious help."

Help Wanted – What Can You Do For The Network?

While we are on the subject of volunteers and the lack of funding for organisations such as ours, it is timely to remind members that the Network is only able to provide the range of services it does because of the generosity of its members and the commitment of its volunteers who unselfishly give countless hours to provide these services. Predominantly, our volunteers have been working for the Network for many years. As many of them experience increasing polio disability they are finding it harder to take on additional duties as the Network continues to grow. So, if you are wondering not what the Network can do for you, but what you can do for the Network, please read on.

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. Again this year we are including with this *Newsletter* a colourful poster promoting the Week. We ask all members to put the poster up somewhere in your local community. If you are willing to talk to local media about your polio story and the work of the Network, please contact Alice on (02) 9747 4694 for a copy of the Network's Media Release and for any background information desired.

Website Editorial Team

The Management Committee and the Network's webmaster, Tony Marturano, wish to set up a Website Editorial Team to assist Tony to identify appropriate content for our website and prepare documents for inclusion on the site. Over several years Tony has spent untold volunteer hours developing our website to its current high standard. Now he is seeking some assistance to help him keep the site up-to-date, relevant, and of continuing interest to members and health professionals alike, as well as polio survivors around the world. We are therefore requesting input from members with internet access, computer and writing skills, enthusiasm, and a little spare time they are willing to give to the Network. The aim is to get together a group of members who, in collaboration with Tony and a Management Committee representative, will not only help develop the website but provide a quality assurance function to ensure the quality of information included. It is anticipated that an Internet mail group will be set up for the interested members to facilitate communication. Helping the Network in this way can be done in the comfort of members' own homes, so limited mobility should not prove a barrier. If you would like to participate in this exciting initiative, please send an email to <gillian@post-polionetwork.org.au> to register your interest, or for more information.

Wanted – Roving Reporters

Recently I have been asked why the *Newsletter* does not include summaries of Network Seminars for the benefit of those members who, because of disability or distance (or indeed both), are unable to attend. As Editor, I appreciate the value of such reports, and would love to include them. They are certainly not omitted for reasons of space; rather, articles can only be included in the *Newsletter* if someone first writes them. For your information, it already takes a week's solid work to put together each issue of the *Newsletter*. This effort is predominantly put in by the Editor, with valued input from Management Committee members, particularly Mary Westbrook who writes at least one article for each issue. This time does not include the day's work to print address labels and for the mail-out team to prepare around 1,000 copies for mailing. Help from members who regularly attend our quarterly Seminars is needed if Seminar reports are to be included in upcoming *Newsletters*. If you are prepared to write an overview of the Seminar topic for inclusion in the subsequent *Newsletter*, could you please contact the Editor. If a few people offer their help, Seminar reports should become a regular feature of the *Newsletter*. It is probably also timely to remind members that Seminars are recorded on audio tape where possible. Please contact the Network for details on obtaining copies of these tapes.

Keep Post-Polio Syndrome on the Political Agenda

With the Federal election now set for 10 November, it's more important than ever to keep post-polio on the political agenda. Please take the time to question the politicians in your local area about what they know of the late effects of polio and, should they be elected, what they are going to do to address the needs of polio survivors. If the politicians know nothing, offer to educate them on the important issues facing us – contact the Network for assistance if necessary. The more members that speak out, the louder our voice will become, and the greater chance we will have of making our needs known. Members who wrote or spoke to their local members over the last twelve months certainly helped to raise the profile of the late effects of polio and of the Network and we are very grateful for their efforts. The election provides a perfect vehicle for further publicising our needs – please don't let the opportunity pass you by.



Member and regular correspondent Ian McKenzie (who recently moved to Kingscliff) put pen to paper soon after receiving and reading the last issue of Network News. He wrote: "Thanks indeed for the bumper issue of the Newsletter. Once again it is full of interest and I have read it from cover to cover. I feel a long way from "home" and sad that I can't attend the Northcott seminar. One of my main concerns in moving away from Sydney was the distance from orthotic services. And as my knee becomes a bit of a bother I was very interested in David Carter's report on his hip replacement. I'm sure I couldn't manage as near as well as he did."

With his letter Ian included the following Letter to the Editor. Thank you, Ian, for taking the trouble to give some feedback on articles in Network News. I encourage more members to follow his lead and tell of their experiences of ageing with polio.

I would think Shirley Whitcroft's presentation to Rotary (*Newsletter*, August 2001) conveyed very well the experience of many who contracted polio - certainly it mirrored mine at about the same time as Mrs Whitcroft's, and evoked memories of the initial high fever and delirium.

And it highlights the thing we all face: the loss of hard-won independence. This raises the important question of accommodation and support in the later years of life.

Being single and having enjoyed many years of living in my own unit, housekeeping and in employment, I have had to accept that, as the prospect of change from crutches to wheelchair looms, this is no longer sensible even if it were possible. And so, on retirement from the workforce came the decision: to seek help to remain "independent" in my unit or move to a residential care facility?

I decided that the first course could lead not to independence but housebound isolation - and further decisions later on. So I looked for other accommodation, at first for something between full self-care and assisted living. But this search was not successful and so I looked at residential care facilities with ease of access being the priority. To cut short a very long story, I have opted for a facility which has level access and covered walkways (bliss!) and an open, pleasant outlook. It is near my sister's home and she has helped me set up the bed/sitter and wheelchair-friendly en suite to best advantage.

Obviously the biggest drawback is the environment of older residents. But with the caring concern of an understanding administrator (who is aware of the non-availability of residential care for the "younger" disabled) I am coping well enough and have privacy and a measure of independence.

No doubt others have chosen different solutions to this problem. Perhaps they will share their experiences through the *Newsletter*.



Reminder – Coming Events – Dates To Remember

28 October	Eastern Suburbs Support Group inaugural meeting (see page 5)
1 – 7 November	Post-Polio Awareness Week (see page 7)
17 November	Picnic at Evangelical Sisterhood of Mary, Theresa Park (see page 4)
16 December	Mini-Conference, AGM and Celebration of Volunteers (see page 2)