

Polio Advisory Committee Minutes for meeting held Friday 6th June 2008

Present

Jill Burn, Margaret Cooper, Geoff Dean, Peter Hudson (Executive Manager, Community Services), Michael Judson (Chairperson), Mary-ann Liethof, Christine McAuslan (Minute Taker), Jo McKenna, Gordon McKinnon and Liz Telford.

Apologies

Marilyn Grimme

Confirmation of Minutes for meeting held 28th March 2008

Moved by Gordon and seconded by Geoff. All in favour

Agenda Items

- **Feedback from Churchill Fellowship Study Tour**

Mary-ann reported, "Absolutely fantastic six weeks that went in a flash. Every single day packed with stuff and couldn't wish for better."

No one Mary-ann visited performs the same role as she does - there is no active outreach. Mary-ann sat in on some PPS clinics whose patients for the most part just 'fell on the clinic'. Despite the fact there are more and more post polios the perception of funding bodies is that polio is 'over' resulting in a lack of available funding. Consequently the lack of outreach means that some post polios only 'happen' on available services.

In the 1990's there were approx. 380 support groups in the United States - there are now only 150. Post Polio Health International provides a good information service to those post polios who find them. An example of the lack of access to post polio support is that there is no post polio clinic in the entire State of New York.

At the PPS Clinic in Montreal, Canada, funding from drug companies is often used for research projects. As there are no drugs known to actually assist with the symptoms of PPS, a research project may be set up for people with Multiple Sclerosis but include polio survivors as one of the control groups, thereby ensuring results are identified for both groups.

Complimentary and alternative medicine was a special feature at one PPS Clinic in Johnstown, Pennsylvania. Mary-ann was also advised about a clinical study on the effects of aromatherapy including a potion for the reduction of pain and a list of recipes for essential oil mixes beneficial to post polio.

Mary-ann now has to write a report for the Churchill Fellowship and when that has been completed a final payment of \$2,000 will be made by the Fellowship. Mary-ann intends to use this to finance the editing of the videos and backing up the tapes on DVD.

Mary-ann asked Michael if he could transfer the USA videos/DVD's received into Australian format.

Geoff moved a motion to congratulate Mary-ann on her initiative in applying for the Churchill Fellowship and the consequent trip.

- **Polio Resources**

Given the number of resources accumulated on the trip, Mary-ann would like to establish a listing of those and existing resources and make that list available on the PSNV website. These publications/ DVDs etc (apart from some rarer resources) could then be made available for loan. PNV volunteer, Jill Pickering, offered to do this as a project when she returns.

Review of previous action plan

- **IT discussion regarding teleconferencing**

Peter Hudson armed with the 'idiot sheet' provided by Michael, spoke to ParaQuad's IT person Steven Rothberg regarding the provision of teleconferencing. Steven's response was that 'it was possible, he has a platform to do it and to advise him when teleconferencing was required'. It was decided to 'experiment' with teleconferencing with Gordon and Geoff at the 27th June meeting. The subject of teleconferencing will be included on the July meeting agenda for the new PAC regarding making this option accessible.

- **VHREO/Taxi scheme**

13CABS advanced cab booking service (ACBS) is trialing a pilot project primarily in the Bayside area. Peter has forwarded this information.

- **Polio Australia MOU**

The MOU is still progressing. All comments from the states are being taken on board. NSW pro bono assistance funding has run out. Michael suggested that clause 16.4 of the Polio Australia Constitution could state that, 'at least 75% of the members of the committee should be polio survivors'. Mary-ann commented that Polio Canada is not comparable to Polio Australia as it is a different model.

Correspondence

- **Ministerial Advisory Council of Senior Victorians**

MP for Narre Warren responded to Barbara Watson's letter regarding issues with changes to the 'Summer Concession'. As from November 1st 2008 the concession title will be altered to 'Medical Cooling Concession'. This concession has now been extended from three to six months and will be available from 1st November to the 30th April of each year. The 17.5% discount on electricity bills is available to eligible concession cardholders for 90 health conditions.

- **Stamp issue for Polio Survivors of Australia**

Australia Post is 'happy to consider' the application for polio survivors stamp but timeline for consideration will not be until mid 2010. The criteria is based on relevant significance and community popularity in the year the application is considered.

- **Dept of Health and Ageing**

A response was received by Pauline Corrigan in regard to her letter to the Dept of Health and Ageing concerning an increase in funding for Polio Services Victoria. The Dept response included background information on polio and polio services.

In relation to the collection of data on the number of polios - it was suggested the FHCFIA may have potential in terms of the National Health Survey. The cost of obtaining information from their referral service is \$360.00.

It was deemed by the PAC that this was 'proving to them what we already know – that there are no comprehensive statistics'.

Margaret will ring the referral service to ascertain if any relevant information might be held.

- **Summer Concession**

4 responses from MPs were received including one from the Minister for Community Services, Lisa Neville, stating that this discount service was not being discontinued. (See item above on Ministerial Advisory Council of Senior Victorians.)

- **State Government Ageing in Victoria-Accessing Health Care round table consultation**

Trish Mallowney has advised that she is attending the Ageing in Victoria-Accessing Health Care round table consultation. Margaret Cooper is also participating and commented that the relevant discussion paper only includes one paragraph referring to disability.

Reports

PQV

Peter Hudson reported that the Budget Building Process is taking place.

Polio Community Officer

Mary-ann reported that there is a Post Polio Clinic Directors' Network which operated via teleconferencing in the US that takes place on Tuesdays at 6.00pm (Wednesdays 8.00pm Aust EST). Jane Henderson from the PSV is on the Network's mailing list but has not participated in the teleconferencing to date.

General Business

Margaret pointed out that in the last edition of ParaGraph (ParaQuad's staff newsletter) incorrect information regarding polio was included. The article attributed initial symptoms of Polio to post polio. Mary-ann will follow up on an erratum to be included in ParaGraph to refute the incorrect information.

Action to be followed up

- Mary-ann to arrange for the editing of the videos and backing up the tapes on DVD MAL
- Transfer the videos filmed on the trip from US to Australian formatting MJ
- Teleconferencing to be organised for 27 June meeting MAL/SR
- Identify with National Health Survey to see if polio statistics are held. MC
- Erratum to be included in ParaGraph MAL

Date of next meeting: 12.00pm for 12.30pm start - Friday 27th June 2008, Board Room, 208 Wellington Street, Collingwood, 3066