

Polio Advisory Committee Planning Day

13 February 2009 / 11.00am to 3.30pm

Mediation Room, Neighbourhood Justice Centre 241 Wellington Street, Collingwood

Attendees

Jill Burn, Margaret Cooper, Geoff Dean, Jane Henderson (PSV), Michael Judson, Mary-ann Liethof, Christine McAuslan (Facilitator), Jo McKenna, Jill Pickering (Recorder), Liz Telford, Peter Willcocks

Apologies

Gordon McKinnon

Introduction

Mary-ann provided an overview of PAC (Polio Advisory Committee) activities during 2008 and issues to consider during today's planning meeting:

- Who & how to utilise PAC member's network contacts
- *Wellness Retreat and Polio in the 21st Century Conference* – Warm Springs, USA in April 09
- Wellness/Polio Day & VicHealth funding proposal for \$8,000
- Presenting polio-related papers to wider audience conferences
- 2009/2010 budget for Special Purpose Post Polio Fund - \$23,000
- Shades of Grey DVD: funding, distribution & editing to targeted audiences such as polio survivors, GP's, allied health professionals, medical school education/libraries
- Supporting PSV (Polio Services Victoria)
- Support Groups for younger polio survivors
- How to reach GP's

What has the PAC Achieved?

- Extended knowledge to general public
- Worked on information to include on PNV (Polio Network Victoria) website
- Arranged radio interviews
- Instigated and applied for June Middleton's Guinness World Record
- Supported Medical Cooling Concession/Networking
- Lobbied politicians for increases in funding for VAEP and PSV
- Contributed information for the development of 2 x PNV brochures & A4 poster
- Wrote letters of support for Community Officer's grant applications
- Worked on themes for Polio Days

- Contributed ideas for PNV's School Speakers project
- Utilised networking contacts (formal and informal)
- Supported the establishment of Polio Australia
- Provided information to assist support groups
- Continuing to work up ideas for Book Project
- Contributed experiences to disability parking & taxi issues
- Suggested items of interest for Polio Perspectives

What are the PAC's Strengths?

- Strong support of PSV
- Stable PAC membership
- Prepared to use networks
- All members are 'doers'
- Provides constructive advice, input and knowledge to assist Community Officer carry out role
- PAC members have continued to develop knowledge
- Members show 'willingness to learn'
- Proactive quest for knowledge and a capacity to respond appropriately
- Commitment and strengths of Community Officer
- Ability to think laterally for ideas and actions to assist polio community
- Provides positive 'value added' face/advocacy for IA
- Has continued active roll for many years
- Being consistent with its goals
- Drive to improve in all areas - not 'tokenistic'
- Committed to Polio Australia Inc.
- Good reputation – PNV shares information and its activities are known state-wide
- Activities continue to be consistent with its goals
- Strong sense of humour across the group

Where is the PAC going? (wish list)

- Need to further increase public awareness
- Continue supporting PNV & PSV
- Acknowledge the trend is occurring to incorporate other disabilities/conditions, especially in the ageing population. (PNV's connection to the Chronic Illness Alliance may impact on this.)
- Need to have a strong relationship with Polio Australia once it gets funded and off the ground.
- Increase GPs knowledge.
- Vital to access/work up knowledge of allied health professionals (in conjunction with PSV) including the fact that, although polio may be eradicated from Australia, those effected *still live on*. Therefore, when an allied health professional works with a client with PPS, they know where to go to access correct information to treat/manage PPS symptoms.
- Assist people with PPS to upskill their self-management techniques by providing self-management information/brochures/training courses.
- Develop professional relationships with main party politicians.
- Promote the achievements of the PAC amongst the Network's Support Groups via Polio Perspectives newsletter and PAC individual member visits to groups.
- Balance information with common sense, i.e. supplements like carnitine and other 'miracle drugs'.

What might impact on this? (i.e. what will stop us from achieving)

- In supplying information to younger migrants – language, literacy and cultural issues
- Resources limiting/impacting on PAC activities;
 - Funding limitations
 - PSV under funding reducing clinical service delivery for people with PPS
 - Competition for the funding dollar/services
 - Community Officer's time restraints
 - PAC members' health, i.e. PPS fatigue, weakness, etc.
 - Meeting space/conditions
- Lack of access to organisations we need i.e. health care professionals, other stake holders
- Lack of cohesion on part of members

Realistic Solutions

- Modify "Shades of Grey" DVD to cater for different target audiences
- Continuing Professional Development for Allied Health Professionals website - new initiative for online education. Jane from PSV is doing a one hour presentation on the website in Gippsland.
- Contacting community radio stations to promote community awareness of PPS
- Properly defined goals
- Have realistic timelines for projects
- Articles - identify appropriate newsletters, e-news website, health-related journals, DHS
- Self-management through support groups, networks, websites
- PAC engaging groups, i.e. allocating individual PAC members to groups
- Include PAC Planning Day notes into Polio Perspectives
- Pursuing funding/resource submissions (i.e. to increased PSV funding)
- Be alert to information about alternative funding sources for Polio Australia as PA may assist all states achieve their full potential
- Identify funding opportunities for specific PNV projects such as:
 - Book project
 - PPS self-management resources
 - Preventative health/wellness resources
 - Ageing well with a disability resources - how to minimise deterioration as we age
 - Advocacy
 - Support and information resources for younger migrant polio survivors

What are the Priorities?

- Wellness/self-management forum – Polio Day
- "Shades of Grey" DVD distributed to networks and edited to half hour format for target groups
- Promotion of PAC to PNV members
- PAC connecting to PSG groups through visits
- Work on attracting new members to PAC to replace departing committee members
- Explore information resources for younger, migrant polio survivors. PSV has 200 clients under 30, many less than 20 yrs. Jane will provide a age/country of origin chart.
- Develop mini survey to find out what young people feel would help.
- PSV to distribute survey - translated in their language, if required.
- Sub-committee to determine timeframe for Stories Project – meeting needs to be arranged.
- Provision of template for permission to reprint stories to be inserted in Autumn 09 Polio Perspectives
- Quality of life for people with post polio syndrome

Short Term

What	Who	When
Information from Warm Springs Wellness Retreat to develop Polio Day/Wellness program	Mary-ann Liethof/Shirley Glance/Fran Henke/Liz Telford	May 09
"Shades of Grey" editing	Peter Willcocks/MAL	TBA
'Stories Project': <ul style="list-style-type: none"> - Consent form template - Check template with others - Invite submissions - Receive / compile / edit - Publish - Distribution 	Margaret Cooper to MAL MAL to sub committee MAL Book Project Sub committee Book Project Sub committee Book Project Sub committee	ASAP By Friday 20 February Include in Autumn PP November 09 Mid 2010 Polio Day / October 2010
Survey for younger people	Jill Burn	Feb 09 PAC Meeting
Promotion of PAC: <ul style="list-style-type: none"> - Print up Planning Day outcome - Invitation to Groups re PAC visit - Provide current visit Schedule 	MAL MAL MAL to Support Groups MAL to PAC	Autumn PP Autumn PP ASAP ASAP

Ongoing

What	Who	When
Funding for PNV for: <ul style="list-style-type: none"> - Books/resources - Publishing Books 	Everyone Jo McKenna talk to DHS	Ongoing February PAC Meeting
Promote PNV activities: <ul style="list-style-type: none"> - Google AdWords Grant - ABC Website - Darebin Council to funding Polio Day/Wellness Forum Promotion 	JB JB LT	March PAC Meeting March PAC Meeting March PAC Meeting
Speak to 'Scribe' contact re publishing book	LT	March PAC Meeting
Identify appropriate resources for younger polio survivors, i.e. chat rooms	Everyone	Ongoing