



Australian Government  
Department of Health and Ageing

# Chronic Disease Self-management/ Lifestyle and Risk Modification Grants ITA – 193/0809 APPLICATION FOR FUNDING

## Summary

**Lead Organisation Name:** Post-Polio Network (NSW) Inc

### Application is for:

- ✓ **Strand 3 – Education of consumers in chronic disease self-management and lifestyle risk factor modification**

**Total amount of Funding Sought: \$ 200,000** (GST Inclusive)

**Duration of Project:** 12 months

### Brief Summary of Project:

Funding is sought for the education of polio survivors and their carers in self-management techniques to stabilise and/or reduce symptoms of the late effects of polio (LEOP) and post-polio syndrome (PPS). Symptoms can include: new muscle weakness/atrophy, chronic fatigue, muscle and joint pain, breathing and swallowing difficulties, inability to regulate body temperature and sleep disorders.

This information will be shared with the participants' health service providers. Many GP's and allied health professionals are unfamiliar with the pathophysiology of LEOP and PPS which often results in ineffective treatment/management and can even cause further damage.

The program will also provide knowledge about stress factors, nutrition, weight management, options for aids and equipment, and home modifications, thereby enabling people to achieve general wellbeing and ensure that they are able to remain as mobile and independent as possible in their own homes.

The program will be delivered as 3-day residential retreats across Australia.

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## 1.5 Brief description of your organisation's main functions and activities

PPN provides information and support to people experiencing LEOP and PPS and their carers, and works in partnership with health care professionals. PPN is a voluntary, self-help, self-funded organisation run by and for polio survivors. The number of polio infections during the epidemics last century mean that polio survivors form the largest single disability group in Australia<sup>1</sup>.

PPN arranges four Seminars in Sydney each year and conducts a biennial NSW Country Conference. PPN publishes a quarterly Newsletter and maintains a comprehensive Website. There is an extensive network of over 30 Support Groups throughout the Sydney metropolitan area, regional NSW and the ACT.

Each year PPN conducts Post-Polio Awareness Week to outreach to and inform unaware polio survivors and their families about the existence of LEOP and PPS and support them in the self-management of this chronic disease. PPN also promotes the importance of immunisation.

PPN initiated the establishment of Polio Australia to develop consistent services and support for polio survivors across Australia.

In common with the other state Networks, PPN is the only organisation in NSW (government or non-government) that provides an information, education and support service for polio survivors, their families and health professionals.

<sup>1</sup> Leboeuf C, *The Late Effects of Polio – Information for Health Care Providers*  
Commonwealth Department of Community Services and Health 1990

## 1.6 Joint Applications

Is this a joint application with other organisations?

**YES**

If YES, please list all of the organisations involved.

### Name of Organisations:

1. Polio Australia Incorporated (letter of support included at Attachment B)

**Note:** Polio Australia Incorporated is referred to in this Application as "Polio Australia" or "PA".

## 2.1.B. PROJECT OBJECTIVES

### Aims

- Expand the range and reach of quality chronic disease self-management (CDSM) interventions and supports available to polio survivors now living with the late effects of polio, and to their carers and families.
- Continue to build the evidence-base on the efficacy of CDSM interventions.

### Objectives

- To ensure that polio survivors, their carers and families are equipped with sufficient knowledge, attitudes and skills to enable them to be more proactive and participate effectively in CDSM and lifestyle risk factor modification.
- Capture evidence of CDSM efficacy via structured feedback from both participants and attending health professionals.

### Outcomes

- ***Increase the awareness and understanding of CDSM by consumers***

Due to a widely held perception that polio is a disease of the past, many health professionals have scant knowledge of the late effects of polio (LEOP) and Post Polio Syndrome (PPS). Whereas LEOP is the result of living for years with a residual physical disability, that is, scoliosis, nerve entrapment due to physical growth retardation/deformation, arthritis, osteoporosis, muscle and joint pain, etc., PPS is the onset of 'new' symptoms brought on by a deterioration in motor neurons, resulting in muscle weakness/atrophy, chronic fatigue, muscle and joint pain, breathing and swallowing difficulties, inability to regulate body temperature and sleep disorders. It is important that polio survivors are made aware of their symptoms if they are to communicate confidently with their health professionals and participate effectively in CDSM. The interaction with a range of health professionals during the 3-day residential will help achieve this outcome.

- ***Improve a consumer's effectiveness in managing their chronic disease, sense of well-being, and health outcomes***

Research<sup>1</sup> and documented experience<sup>2</sup> has proven that the most effective strategies to minimise and/or stabilise the symptoms of PPS is through self-management and lifestyle modification. For many polio survivors, PPS symptoms were an unexpected and cruel flashback to the original poliovirus infection, which left them paralysed, stigmatised and isolated from family, friends and society. Understanding and overcoming depression and denial is paramount to achieving optimal wellbeing. Learning self-management techniques such as 'pacing' and relaxation/meditation can assist with both physical and psychological health and wellbeing.

- ***Have an appropriate impact on the consumer's health service usage***

Medication may be used to reduce inflammation-related pain and swelling but without proactive self-management techniques such as 'pacing' activities of daily living, PPS can progress to a level resulting in severely limited mobility requiring additional aids, equipment and care, and can also lead to falls/bone fractures, weight gain, risk of diabetes and hypertension, and premature and often inappropriate institutional care. The knowledge, attitude and skills gained in this 3-day retreat will result in polio survivors having a clearer understanding of the longer term personal health and health resource implications associated with their condition, highlighting the benefits of CDSM.

<sup>1</sup> Roller S et al, *Wellness for Women with Polio: A Holistic Program Model (A Report of Initial Findings)* Post-Polio Health, Vol 17, No 3, St Louis MO USA, Summer 2001

<sup>2</sup> Thompson M, *Polio – the living legacy*, Post-Polio Network (NSW) Inc, Sydney 2007, ISBN 9780646480558

### 2.1.C. MEETING PROGRAM PRIORITY AREAS

***Please describe how your project will meet program priority areas and, if applicable, complement and/or enhance existing programs in relation to chronic disease prevention and management.***

The 3-day retreats will be run in all States: 1 TAS, 1 SA, 1 VIC, 1 WA, 1 NSW, 1 QLD, for up to 40 participants each, directly assisting 240 people with potential flow-on benefits to hundreds more as a result of attendees disseminating the CDSM principles learned. They will incorporate the involvement of state-based health service providers, including but not limited to:

- Facilitators trained in Better Health Self Management such as that offered by Arthritis/Osteoporosis organisations, promoting active self management techniques
- On site Yoga instructors, Osteopaths, Acupuncturists, Massage therapists, and Podiatrists to demonstrate alternative methods for relieving pain and assisting participants to become more attuned to their bodies
- Sessions presented by Physiotherapists, Respiratory Specialists, Dieticians/Nutritionists, Speech Therapists, and Arthritis/Osteoporosis organisations to indicate the scope of these health service providers and how their intervention can be integrated in the practice of CDSM
- Sessions presented by Occupational Therapists and Orthotists to explain the benefits of various aids and equipment in remaining as active, mobile and independent as possible in their own homes and the community
- Presentations by Pharmacists and Naturopaths to discuss the effects of prescription, over the counter, and Complimentary and Alternative Medicine (CAM) medication and contraindications for LEOP and PPS symptoms, i.e. increased muscle weakness, fatigue and breathing difficulties
- Presentations by Home and Community Care service providers, State Departments of Human/Community Services, and Centrelink etc. to ensure people are accessing services that will assist in their CDSM

Relevant CDSM education awareness packages would be designed incorporating hard copy information, recommended services, reading and website references, presenters notes/information, and follow up progress charts, to ensure knowledge of CDSM options and techniques are accessible after the retreat.

Polio survivors are made up of target groups including:

- many from CALD populations – Polio Services Victoria (PSV), a clinical service of St Vincent's Hospital Melbourne, has 200 survivors listed under the age of 30 years old; these people would be accessed through PSV with a view to facilitating a separate, demographically appropriate retreat at a later date
- those experiencing socio-economic disadvantage due to living on Disability Pensions
- men, who have a slightly higher disposition to contracting the poliovirus
- people with physical impairments, and their carers
- there are no known records indicating the number of Aboriginal and Torres Strait Islander peoples who contracted polio and are now living with its late effects, however we would endeavour to do specific outreach to quantify the need for this demographic.

In addition to NSW, Polio Networks exist in each State and most have websites that will be used to recruit participants. The Network websites will direct users to Polio Australia's website on which the CDSM information package will be uploaded.

**2.1.D. PROJECT PLAN**

<b>Project objectives</b>	<b>What are the key strategies you intend to undertake in order to meet these objectives</b>	<b>Please outline the activities you will undertake for each strategy</b>	<b>How will you know if you have achieved your objectives</b>	<b>Timeframe</b>
1. Establish staffing, administration resources and management systems	1.a Appoint Project Manager to design, deliver and manage all aspects of the project in consultation with all stakeholders	1.a.i Appoint Project Manager, secure suitable office space	Project manager appointed and work premises established	end June 09
		1.a.ii Purchase project equipment and supplies	Project equipment and supplies purchased, recorded and operational	end June 09
	1.b Recruit part time Project Officer	1.b.i Create position description, advertise and interview suitable Project Officer	Position description completed, position advertised, applications received and interviews arranged	mid July 09
		1.b.ii Employ Project Officer and instruct in functions and systems to be set up	Project Officer commenced and administrative systems established	end July 09

<b>Project objectives</b>	<b>What are the key strategies you intend to undertake in order to meet these objectives</b>	<b>Please outline the activities you will undertake for each strategy</b>	<b>How will you know if you have achieved your objectives</b>	<b>Timeframe</b>
<b>2. Design 3-day residential program</b>	<b>2.a</b> Determine appropriate content	<b>2.a.i</b> Consult with State Polio Networks	State Polio Networks contacted and recommendations received	end July 09
		<b>2.a.ii</b> Consult with a range of organisations and research other successful residential models	Other residential models identified and concepts analysed and incorporated if appropriate	end July 09
	<b>2.b</b> Identify special needs criteria to ensure full participation	<b>2.b.i</b> Consult cross-section of prospective attendees via Polio Network Support Groups	Polio Network Support Groups contacted and recommendations received and taken into consideration	end July 09
		<b>2.b.ii</b> Research programs and registration forms for other successful residential models	Other residential programs and registration details analysed and incorporated if appropriate	end July 09

Project objectives	What are the key strategies you intend to undertake in order to meet these objectives	Please outline the activities you will undertake for each strategy	How will you know if you have achieved your objectives	Timeframe
3. Identify suitable retreat venues in each State	3.a Determine available venue options and locations of each	3.a.i Consult with State Polio Networks for recommendations and suggestions	State Polio Networks contacted and recommendations received for consideration	end August 09
		3.a.ii Research venues on internet and contact by email/phone for further details and availability	Suitable venues identified, contacted and availability recorded	end August 09
	3.b Research venues for relevant facilities and accessibility	3.b.i Consult with State Polio Networks and local community health/disability service providers for suggestions	State Polio Networks and community health/disability service providers contacted and recommendations received for consideration	end August 09
		3.b.ii Visit selected venues to discuss specific requirements	Schedule of visits arranged and completed	mid September 09

Project objectives	What are the key strategies you intend to undertake in order to meet these objectives	Please outline the activities you will undertake for each strategy	How will you know if you have achieved your objectives	Timeframe
4. Confirm participation in and clarify role of health service providers	4.a Locate, contact and secure participating state-based health service providers	4.a.i Consult with State Polio Networks and local community health/disability service providers for recommendations and suggestions	State Polio Networks and community health/disability service providers contacted and recommendations received for potential inclusion in program	end August 09
		4.a.ii Visit selected service providers to discuss specific requirements	Schedule of visits arranged and completed, with confirmation of participation provided by service providers.	mid September 09
	4.b Provide relevant supporting information to health service providers	4.b.i Identify and/or supply recommended DVDs, presentations, reading material and websites specific to LEOP and PPS, if required	Service providers contacted and in receipt of supporting material.	end September 09
		4.b.ii Provide service providers with full details of residential program	Service providers contacted and in receipt of relevant details.	end September 09

<b>Project objectives</b>	<b>What are the key strategies you intend to undertake in order to meet these objectives</b>	<b>Please outline the activities you will undertake for each strategy</b>	<b>How will you know if you have achieved your objectives</b>	<b>Timeframe</b>
<b>5. Maximise registration for retreats</b>	<b>5.a</b> Promote retreats	<b>5.a.i</b> Create promotional material	Promotional material completed	end September 09
		<b>5.a.ii</b> Provide promotional material to all State Polio Networks for inclusion in newsletters and websites and for local advertising	Polio Networks in receipt of promotional material and broadcast via relevant communication channels	early October 09
	<b>5.b</b> Identify participant numbers	<b>5.b.i</b> Receive registrations, record details and confirm attendance up to 40 participants per retreat	Participant registrations received and recorded	progressive to late March 10
		<b>5.b.ii</b> Identify special needs of participants and arrange necessary equipment and personal care/support workers as required	Special needs noted, arrangements made with relevant organisations and communicated to venues	progressive to late March 10

<b>Project objectives</b>	<b>What are the key strategies you intend to undertake in order to meet these objectives</b>	<b>Please outline the activities you will undertake for each strategy</b>	<b>How will you know if you have achieved your objectives</b>	<b>Timeframe</b>
<b>6. Produce CDSM information</b>	<b>6.a</b> Complete CDSM education awareness package	<b>6.a.i</b> Source relevant LEOP and PPS information for inclusion in package	LEOP and PPS information identified	end October 09
		<b>6.a.ii</b> Request discipline-specific CDSM information from participating service providers	Participating health service providers contacted and CDSM information received	end October 09
	<b>6.b</b> Produce sufficient packages for retreat participants	<b>6.b.i</b> Source and request quotes from printing/collating organisations	Printers contacted and quotes received for selection	early November 09
		<b>6.b.ii</b> Engage organisation to produce packages	Selected organisation provided with material and timeframe for completion established	early November 09

Project objectives	What are the key strategies you intend to undertake in order to meet these objectives	Please outline the activities you will undertake for each strategy	How will you know if you have achieved your objectives	Timeframe
7. Facilitate six x 3-day residential retreats – one in each State	7.a Project Manager to attend each residential to coordinate activities	7.a.i Liaise between participants, venue representatives and health service providers to assist with any issues requiring clarification or that need to be attended to	All those connected to the retreat are clear about involvement and expectations	TAS - late Nov 09 SA - late Jan 10 VIC - late Feb 10 WA - late Mar 10 NSW - mid Apr 10 QLD - early May 10
		7.a.ii Adjust timing, location and participation levels of scheduled activities, if required	Activities run smoothly and any issues attended to promptly	
	7.b Ensure all systems are in place to maximise CDSM residential experience for all participants	7.b.i Have all relevant administration documentation, CDSM packages, registration and special needs, contact numbers, audio/visual equipment requirements, and aids and equipment available for instant access	Administration and support systems organised and readily accessible, and strategies in place for any unexpected circumstances.	
		7.b.ii Provide opportunities for participants to give constructive feedback – written and verbal – at each retreat to take into account for all other retreats	Feedback forms distributed and returned for evaluation and consideration – any verbal comments noted and incorporated in overall evaluation	

<b>Project objectives</b>	<b>What are the key strategies you intend to undertake in order to meet these objectives</b>	<b>Please outline the activities you will undertake for each strategy</b>	<b>How will you know if you have achieved your objectives</b>	<b>Timeframe</b>	
<b>8. Conclude program</b>	<b>8.a</b> Provide Final Report	<b>8.a.i</b> Prepare comprehensive report on actual performance against Guidelines and Standards and Aim of the Project	Final Report sent and received by Dept of Health and Ageing	end May 10	
		<b>8.a.ii</b> Prepare a certificate confirming that funds were spent appropriately, legal obligations were met, capacity to pay all debts	Certificate sent and received by Dept of Health and Ageing	end May 10	
	<b>8.b</b> Provide End of Financial Year Report	<b>8.b.i</b> Prepare financial accounts including statement of balance, actual performance against the Guidelines and Standards and Aims of the Project, and meeting current liabilities	End of Financial Year Report sent and received by Dept of Health and Ageing	Annual Report, Audited Accounts and Auditor's Report sent and received by Dept of Health and Ageing	end Sep 10
		<b>8.b.ii</b> Arrange audit of financial accounts			

## 2.1.E. BUDGET

Resource (itemised)	Year 1	Total
<b>Staffing costs (GST Exclusive)</b>		
Salaries – F/T Project Manager (35 hrs/week), P/T Project Officer (15 hrs/week) <i>See Note [1]</i>	\$ 23,248	\$ 23,248
<b>Other employee costs</b>		
Superannuation (9%) and other on-costs (incl Workers' Compensation insurance) <i>See Note [1]</i>	\$ 3,487	\$ 3,487
<b>Other costs (GST Exclusive)</b>		
Insurance upgrade <sup>1</sup> – Public Liability and Directors' Liability	\$ 3,820	\$ 3,820
Travel – airfares to 5 States	\$ 4,076	\$ 4,076
6 x 3-Day Residential Retreats – including all venue costs, session and health/disability service provider costs, marketing, promotion	\$ 127,909	\$ 127,909
Participants' special needs costs – including support workers, equipment hire	\$ 9,709	\$ 9,709
Printing, postage and stationery	\$ 6,545	\$ 6,545
6 x State Networks admin support costs	\$ 5,455	\$ 5,455
<b>TOTAL funding costs (GST Exclusive)</b>	<b>\$ 184,249</b>	<b>\$ 184,249</b>
<b>+ 10% GST</b>	\$ 15,751	\$ 15,751
<b>TOTAL PROJECT COST (GST Inclusive)</b>	<b>\$ 200,000</b>	<b>\$ 200,000</b>

### Notes:

- [1] Salaries and on-costs are given above at 33.3% of actual budgeted expense. The remaining 66.6% (\$53,480) will be met from the budgeted income given below.
- [2] Budgeted office and administrative expenses of \$15,200 (including GST) are not included above. These costs will be met from the budgeted income given below.
- [3] Budgeted income for this project comprises:
- |  |           |
|--|-----------|
| Participant contribution towards venue costs (accommodation and meals)         | \$ 55,500 |
| Corporate partnership contributions  | \$ 9,705  |
| <sup>1</sup> Post-Polio Network (NSW) Inc contribution towards insurance costs | \$ 2,475  |
| Polio Australia Inc contribution towards administrative expenses               | \$ 1,000  |

<b>Total budgeted income (including GST)</b>	<b>\$ 68,680</b>
<b>Total funding sought (including GST)</b>	<b>\$ 200,000</b>
<b>Total budgeted expenditure (including GST)</b>	<b>\$ 268,680</b>

## 2.2.A. PROJECT MANAGEMENT

- **Other training / activities your organisation has undertaken**

**1996** Arranged and managed 3-day residential International Post-Polio Conference with international key-note speakers, seminars, workshops, conference publications – 150 participants.

**2007** Arranged and managed 2-day Polio Australasia Conference with key-note speakers, seminars, workshops. The 40 participants unanimously resolved to formally establish Polio Australia. Formulated policy and provided future direction for development of services.

**Country Conferences:** Canberra 1998, Dubbo 2003, Newcastle 2005, Ballina 2007, Wagga 2009. 1 or 2-day forums with keynote speakers from around Australia, Support Group workshops, member networking – average participants 80.

**Metropolitan Seminars/Conferences:** Four conducted each year since 1989. Forums for presentation and discussion on specific issues relating to management of LEOP – average participants 40-60.

**Collaboration with Polio Australia** for this project brings additional experience from other states. Polio Network Victoria's Community Officer visited North American Post Polio Institutes in 2008 on a Churchill Fellowship and presented her findings and recommendations for a CDSM approach at 6 sessions during Queensland's Post-Polio Awareness Week, a joint NSW/VIC Polio Day in Albury, and at PPN's AGM/Seminar.

- **Proven ability to manage program of a similar size**

For twenty years PPN has actively initiated and conducted training and development activities for members. Not only have the activities been conducted on modest cost-neutral budgets but have been keenly sought by members and well supported throughout the state.

Major conferences and initiatives have been diverse in their scope, effectively organised, promoted and been subject to rigorous financial control as reflected in PPN's Annual Reports and audited financial Statements.

The scope of the current proposal is well within the capacity of the organisation as the personnel involved have proven ability and experience to manage the program.

- **What risks have you identified that may impact on this project**

- Some polio survivors are 'jaded' due to lack of medical assistance and sceptical about the CDSM concept.
- Survivors may be in denial about their symptoms and unwilling to participate.
- Survivors may not be aware that new weakness etc is PPS-related.
- Survivors experiencing PPS symptoms may be unsure if they had poliomyelitis due to poor records, stigma and family fear.
- Locating suitable, accessible facilities.
- Cost of participation.

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• **How will any risks be mitigated?**

- State Networks provided with specific CDSM information for use when promoting the retreats.
- Advertising in the press, through Support Group Conveners and ongoing information sessions.
- Symptoms of LEOP and PPS clearly listed in all advertising and promotional material with recommendations to contact State Post-Polio Networks for further information.
- Clear communication with venues about the special requirements of polio survivors and the retreats and conducting site visits to ensure these needs are able to be met.
- Attendance fees structured to ensure those on a low income are not disadvantaged and can participate.

• **Will you be working with any other organisations?**

Consultations will occur with all individual State Networks and other organisations running CDSM program components.

• **How will the project be managed?**

A full-time experienced Project Manager will manage the design and delivery of the retreats, regularly report on program progress, performance against budget, issues and outcomes to a PPN/PA Steering Committee and provide progress reports and a final report to the Department of Health and Ageing in accordance with stipulated timeframes.

## 2.2.B. FINANCIAL MANAGEMENT

***Provide examples of how similar projects have been effectively managed***

Since PPN was established in 1989, all its programs have been funded by membership subscriptions, donations, occasional small bequests, and a limited number of one-off grants and donations from philanthropic organisations. PPN's financial accounts are rigorously audited every year.

Notwithstanding the absence of recurrent funding, PPN has a very strong Balance Sheet as reflected in the accompanying audited financial statements. Over the last twenty years, PPN's Management Committees have carefully managed the funds entrusted to them and paid scrupulous attention to their fiscal responsibilities to both the organisation and the many projects PPN has undertaken in support of polio survivors.

Projects have ranged from quarterly Seminars with local, national and occasionally international speakers, to both national and international conferences. Activities have been conducted with limited resources yet have attracted up to 150 participants and have operated on a break-even basis or better.

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A number of grants have been received through the Community Development Support Expenditure scheme for the provision of specific information and education activities and resources. These include the research, authorship and publication of information booklets, medical alert cards and brochures specifically targeted at health professionals. Seeding grants for the establishment of a number of regional peer support groups in NSW have also been received. All grants were carefully allocated to achieve the required outcome from the resources available and all have been duly acquitted.

Donations of up to \$20,000 from philanthropic trusts have been devoted to achieving the specific objectives outlined in the grant application and faithfully expended in accordance with the stated guidelines.

PPN received a grant from the Department of Family and Community Services in support of the very successful national Polio 2000 Conference. The grant was utilised for the purpose for which it was granted and properly acquitted.

### **2.2.C. ORGANISATIONAL SUPPORT/CAPACITY**

#### ***Are there any potential or actual competing interests; and how will they be managed?***

PPN and Polio Australia (comprising all state Networks) are the only organisations in Australia representing the interests of polio survivors and providing information, education and support services. The proposed project is coincident with both organisations' aims and objectives and as such there will not be any potential or actual competing interests.

The Management Committees of both PPN and PA are either polio survivors who are themselves experiencing the late effects of polio, or people who work with polio survivors, their families and carers. This, of course, puts both Committees in the unique position of fully understanding the CDSM needs of the consumers and carers with whom the project will be working. Both organisations are committed to seeing the project succeed in all states. The Steering Committee drawn from the PPN and PA Committees will be responsible for providing leadership to the staff and ensuring that the full Management Committee of each organisation is kept informed of both program and financial progress, together with any arising issues, to enable their governance responsibilities to be met.

With respect to staffing, PPN will be engaging staff whose sole responsibilities will be the design, delivery and monitoring of the tasks required to achieve the project's aims. The project will be led by a full-time experienced Project Manager who must be conversant with the special issues that polio survivors face and their CDSM education needs, experienced in assembling the necessary resources to conduct residential programs, and able to identify and secure the services of appropriate CDSM presenters for education sessions across Australia. A part-time Project Officer will complete the team and will provide administrative support for the project logistics. Neither of the staff will be working on tasks unrelated to this project and therefore there will be no potential or actual competing interests.

## 2.2.D. MONITORING AND REPORTING

- ***How will the project be managed?***

The Project Manager will manage the design and delivery of the retreats, including information for and interaction with consumers and carers, and negotiations and arrangements with presenters. A Steering Committee comprising members from the PPN and PA Management Committees will be established to provide leadership to the staff, a sounding board for ideas, and access to the organisations' Management Committees as required. By continual review of progress against every aspect of the Project Plan, any required fine-tuning will be readily apparent and easily implemented.

- ***Who will be responsible for reporting?***

The Project Manager will regularly report to the Steering Committee on program progress, performance against budget, emerging issues and outcomes. The Project Manager will also provide progress reports and a final report to the Department of Health and Ageing in accordance with stipulated timeframes. The Steering Committee will report to the full PPN and PA Management Committees, who will in turn report to the Department of Health and Ageing, and to their members and the wider community, via their Annual Reports and audited Financial Statements.

- ***How will the project be evaluated? Is there an evaluation plan?***

The project will be evaluated by reviewing each step of the Project Plan to determine whether the stated objectives have been achieved in the time frame specified.

The evaluation plan will report against the following criteria:

- \* Assess performance of personnel recruited to key positions
- \* Determine whether all six retreats were able to be conducted as planned
- \* Assess the effectiveness of the participation of the health service providers
- \* Evaluate the effectiveness of the three day residential program
- \* Review the relevance of the CDSM information provided
- \* Review whether the targeted number of participants attended each retreat
- \* Utilise participant evaluation forms to determine whether the retreat program met expectations
- \* Review expenditure to confirm that the program remained within the allocated budget

### 2.3.A. SUSTAINABILITY

**Please describe how your project outcomes could/will be sustained after the funding for this project has been expended.**

***Increase the awareness and understanding of CDSM by consumers***

The CDSM information elicited from these retreats will be shared with the Australian polio community via:

- uploads on state Post-Polio Network and Polio Australia websites;
- articles in post-polio newsletters;
- requests to health professionals presenting at the retreats to write about the experience in their respective disciplines' publications;
- participant talks at post-polio support group meetings;
- information packages containing self-management strategies and techniques provided to polio survivors attending retreats, and uploaded to PPN and Polio Australia websites for general access; and
- continued outreach to polio survivors currently unaware of PPS in the community, particularly younger CALD survivors and Aboriginal and Torres Strait Islanders, to determine the need to apply for funding to facilitate tailored retreats.

***Improve a consumer's effectiveness in managing their chronic disease, sense of well-being, and health outcomes***

When polio survivors congregate at Post-Polio Network activities, the opportunity is provided to discuss psychological reactions to their earlier experiences and to their current struggles with the late effects of polio with people who "know". Incorporated in these retreats is a component that explores issues for polio survivors such as coping with the emotional and interpersonal aspects of LEOP and PPS; managing stress and depression; negotiating relationships with family and friends; developing a positive self-concept; and improving doctor-patient communication.

Sustained outcomes from this segment include:

- increased quality of life for polio survivors and their carers/families: monitored by 6 and 12 month follow up questionnaires sent by Polio Australia to both polio survivors and their "significant others" who attended the retreats;
- decrease in stress levels including mutual understanding of realistic capacity and expectations by family and friends: monitored by 6 and 12 month follow up questionnaires;
- renewed positive outlook on their future, living and thriving with the late effects of polio: examples to be solicited in questionnaires; and
- increased confidence in expressing themselves resulting in improved relationships with health professionals: examples to be solicited in questionnaires.

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***Have an appropriate impact on the consumer's health service usage***

The proposed retreats are designed to bring polio survivors and health professionals together to share ideas and learn new techniques for living and thriving with the late effects of polio using a CDSM model. Although there are very few health services knowledgeable about working with polio survivors, those health professionals who have participated in Post-Polio Network activities have reported that they gain an increased awareness and better resources to assist their patients. Polio survivors themselves learn more about how to manage the late effects and pass that information on to their health professionals, thereby increasing the knowledge base across the health sector.

Consequently, sustained outcomes include:

- reduced impact on the health, disability and aged care sectors as more polio survivors learn how to effectively manage their chronic condition: before and after examples to be solicited in questionnaires; and
- polio survivors empowered to educate their own health practitioners using accurate, well researched information: examples to be solicited in questionnaires.

## 2.3.B. ADDITIONAL COMMENTS

### ***Any other relevant information relating to your project proposal***

Up to 40,000 people were diagnosed with paralytic polio in Australia between 1930 and 1988. This figure must be increased 100-fold to obtain the estimated number of infected cases during the same period (up to 4 million people), and they do not include people who contracted polio overseas and who have since entered Australia <sup>1</sup>.

Resulting from the polio epidemics, there are tens of thousands of people with a wide range of disabilities which restrict and impede their daily lives. In addition, whether they contracted paralytic or non-paralytic polio many are now experiencing the late effects <sup>2</sup> and are increasingly seeking information on management strategies. Many polio survivors who walked independently must now use braces, crutches or wheelchairs – this is often viewed as being a failure and is fought against. The cost to the taxpayer of acute care episodes due to falls, for example, is significant. All survivors are increasingly forced to rely on family support, including their ageing partners, to undertake the activities of daily living. Some who previously neither experienced nor showed any signs of disability are being forced to use ambulatory aids and make changes to their work and home lives. Properly supported, lifestyle changes enable polio survivors to effectively self-manage their chronic condition.

For the last twenty years, volunteer post-polio consumer support Networks in Australia have been providing information and education to fellow polio survivors, their families, carers and health professionals regarding the symptoms and management of the late effects. Several state Networks have published research which quantifies the extent and impact of the late effects amongst their members.

Effective self-management of their chronic condition is of paramount importance to polio survivors. Failing this, many are forced into early retirement with consequent loss of financial security and self esteem, or face premature admission into nursing homes as they lose the ability to care for themselves, putting further pressure on an overburdened health system.

This innovative project provides excellent value for money. It will directly assist up to 240 polio survivors and their carers across Australia, and indirectly assist hundreds more as the management strategies are disseminated to families, carers, the wider polio community and health professionals.

The project will be managed by PPN, a financially viable consumer organisation with exemplary project and financial management credentials and a twenty-year history of education and support of polio survivors. PPN is very well regarded in the community as evidenced by its patron, Sir Gus Nossal. The program will be effectively delivered through a collaborative partnership with Polio Australia Inc. All state Networks are members of Polio Australia and are committed to seeing the project succeed in every state.

Tens of thousands of polio survivors throughout Australia are living with a chronic condition but as the late effects take increasing toll on them they must learn new strategies to help them self-manage their condition and prevent further deterioration. Funding of this project will enable many to take the first steps towards a better quality of life.

<sup>1</sup> Leboeuf C, *The Late Effects of Polio – Information for Health Care Providers*  
Commonwealth Department of Community Services and Health 1990

<sup>2</sup> Four papers in *American Journal of Physical Medicine and Rehabilitation* (Volume 79, part 1, 2000)