



# **POST - POLIO NETWORK (NSW) INC.**

Supporting polio survivors and their families since 1989

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Budget Policy Division  
Department of the Treasury  
Langton Crescent  
PARKES ACT 2600

Attention: Ms Penny Sirault

Dear Ms Sirault

I am writing further to my letter dated 17 January 2008 wherein I forwarded our funding submission for inclusion in the 2008-09 Budget.

In my desire to get the submission in before the deadline, I neglected to say that our funding request is for a pilot program and should be considered in that context.

Thank you again for the Treasurer's commitment to consulting with the community regarding priorities for the Government's first Budget.

Please do not hesitate to contact me if you require any further information.

Yours sincerely

Gillian Thomas  
President

21 January 2008



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Attention: Ms Penny Sirault

Dear Ms Sirault

We much appreciate the Treasurer's commitment to consulting with the community regarding priorities for the Government's first Budget.

Our attached submission deals with a critical, yet to-date ignored, community priority. Polio might be forgotten in today's society, but Australia's tens of thousands of polio survivors must not be forgotten any longer. A nationally-consistent approach to the diagnosis and management of the debilitating late effects of polio is long overdue. Our submission seeks funding to enable Polio Australia to develop and present a comprehensive education program that will ensure all Australian polio survivors have access to adequate support and information together with comprehensive and consistent health care from a range of well-informed and educated professionals.

We hope that our submission will be considered favourably for inclusion in the 2008-09 Budget and look forward to learning the results of the Treasurer's deliberations.

Our submission is necessarily brief but please do not hesitate to contact me if you require any further information.

Yours sincerely

Gillian Thomas  
President

17 January 2008



*Proposal*

# **Polio Australia**

## **A National Educator**

on the late effects of polio



**Polio ... forgotten, but not gone**



## Executive Summary

For many of Australia's polio survivors, the late effects of polio are causing significant and ongoing problems which impact on all aspects of their daily lives. Together with peer support and information, many of the symptoms associated with the late effects of polio can be managed through the coordinated efforts of medical and health professionals. However, there is minimal specialist knowledge and support available or accessible.

In order to help themselves, polio survivors in each state have formed 'Post-Polio Networks' over the last 20 years. These Networks have been proactive in a number of areas including developing support networks, disseminating information, and arranging seminars and conferences. Unfortunately, in the majority of states, the Networks are operating without any funding and this is not a sustainable or adequate model of support.

In May 2007 at their national self-funded 'Designing a Future' conference, the Networks resolved to establish a national organisation *Polio Australia* to articulate the needs of polio survivors in Australia in the development and presentation of comprehensive education and training programs to Australian health professionals. This proposal seeks \$2 million over four years from the federal government to achieve a comprehensive set of outcomes for polio survivors, their families and carers, health professionals and the community. Polio Australia's education programs will lead to prompt diagnosis and effective management of the late effects of polio and will realise savings in other areas of government expenditure. Achievement of Polio Australia's aims as outlined will provide a basis for seeking ongoing funding from both the government and corporate sectors to ensure future viability and sustainability.

Polio Australia's mission will be enabled by the requested funding and will ensure that all polio survivors have access to adequate support and information together with comprehensive, consistent health care from a range of well-informed and educated professionals.



## Contents

### Submission – Polio Australia

Introduction .....	Page 1
Polio Australia .....	Page 2
Education is the key .....	Page 2
The vision .....	Page 2
Aims of Polio Australia .....	Page 3
A look at the late effects of polio .....	Page 4
Conclusion .....	Page 5
Appendix A	What is polio?
Appendix B	The late effects of polio – some statistics



## Introduction

Polio (poliomyelitis or infantile paralysis) is now a disease that has virtually been forgotten by our community and health professionals. Although vaccination programs beginning in the late 1950s have prevented new infections in Australia, polio survivors form the largest single disability group in the country. Professionals with first-hand experience of the disease have long since retired and there is an urgent and growing need for Australians to become re-acquainted with polio and its late effects.

Over the last twenty years much attention has been drawn to the development of new, previously unrecognised, symptoms which occur in people who were thought to have reached a stable level of recovery after the acute disease. Many polio survivors who have emerging symptoms still report difficulty in obtaining correct diagnosis and treatment. The large number of survivors who are now experiencing new symptoms has transformed the problem from an individual predicament to a social concern.

In recognition of the need for support for those experiencing the late effects of polio, Post-Polio Networks were established in all Australian states in the late 80's and early 90's. These groups continue to provide information and support services on a voluntary basis to large numbers of their peers and health professionals, generally without the benefit of any public funding.

In May 2007, the state Post-Polio Networks met together in Sydney at a self-funded national polio conference, 'Designing a Future'. Here, the Network representatives resolved to establish a national educator, 'Polio Australia'.

This submission seeks funding to enable Polio Australia to fulfil its mandate of putting in place educative programs for health professionals, polio survivors and the community which will in turn lead to the provision of appropriate, adequate and consistent health and ancillary services to polio survivors throughout Australia.



## **Polio Australia**

### ***Education is the key***

**\$2 million dollars over 4 years is being requested for a federally-funded education program designed, managed and presented by Polio Australia in collaboration with all stakeholders. The program will inform and educate doctors (including General Practitioners and a range of specialists), polio survivors and the general public about the late effects of polio and how to manage them.**

**A public / private partnership is also envisaged whereby “in kind” support is provided by television, radio and other media outlets.**

**A comprehensive establishment and annual budget is available on request.**

### ***The vision***

For a number of years the Post-Polio Networks of Australia have been seeking sustainable solutions for supporting polio survivors through education at many levels.

The ‘Designing a Future’ conference was organised by the NSW Network and staged in Sydney in May 2007 with the aim of ensuring polio survivors receive the information, services and support they need into the future. This conference was timely, in that the state Networks are all reaching a critical stage as the volunteers who manage them are ageing and becoming more affected by the late effects of polio. In addition, most of the Networks receive minimal or no government funding and rely on the contribution of these ageing volunteers to maintain their services.

The ‘Designing a Future’ conference produced a number of positive outcomes, including the resolution that Polio Australia be established. Its major goal is to inform health professionals and the community about the late effects of polio and their management through the identification, development and presentation of nationally-consistent education programs.



## ***Aims of Polio Australia***

Polio Australia is currently being formally established.

Objectives for the national body include:

- Provide information, education and training to General Practitioners and a range of medical specialists and other health professionals to improve the diagnosis and management of the late effects.
- Educate and inform polio survivors, their families and carers, and the community at large about the late effects of polio (through, for example, an annual co-ordinated national Post-Polio Awareness Week).
- Target culturally and linguistically diverse (CALD) and Aboriginal and Torres Strait Islander (ATSI) polio survivors and provide outreach support to ensure their diverse needs are being met in a culturally appropriate way.
- Advise governments on policy development and programs in relation to the late effects of polio.
- Facilitate the provision of appropriate and consistent health and other support services across all states and territories to improve the treatment and management of the late effects of polio.
- Assist the state Networks to support polio survivors and their families, friends and carers at the local level.
- Facilitate and encourage the co-ordination and further development of activities within and between the state Networks.
- Support and promote polio immunisation at a national level, and provide assistance to the state Networks to do so at the local level.
- Stimulate research into the late effects of polio.



## A look at the late effects of polio

Polio (described in more detail in **Appendix A**) was previously considered to be a self-limiting disease, once the acute stage was over. The amount of residual damage determined the degree of recovery, which was thought to be stable once optimum function had been achieved. However, it is now well established that polio has a second, slowly progressive degenerative phase, unrelated to normal ageing.

As time passes, an increasing number of previously “stable” persons with a history of polio infection report unexpected new symptoms. The time lag from the initial infection to the second phase varies but is commonly approximately 30 years. The onset is usually slow and steady. It may occasionally develop suddenly and progress at an irregular pace. Symptoms sometimes commence after a period of physical or emotional strain, or after a period of immobility (for example: disease, surgery).

Symptoms include unaccustomed fatigue unrelated to activity, decreased strength and endurance, pain in muscles and/or joints, an inability to stay alert, weakness and muscle atrophy, muscle and joint pain, muscle spasms/twitching, respiratory problems, swallowing or speaking difficulties, depression and anxiety.

Since the 1980s there has been a marked increase in the number of scientific articles and reports in the popular press on this subject. The most widely accepted hypothesis for the cause of the late effects is that they result from the degeneration of motor neurones which sprouted new connections to compensate for the nerves killed by the polio virus. Other contributing factors in the development of the late effects may also include the overuse or disuse of muscles, and the ageing process. However, ageing alone is not the cause, as new symptoms may, in fact, commence at any age and commonly well before the age of 60, when significant age-related loss of motor neurones ordinarily occurs.

People who were diagnosed with paralytic polio and have obviously affected limbs still have trouble convincing some doctors that the late effects are “real” and not psychosomatic or simply the result, for example, of using crutches for too long. People with a history of non-paralytic polio have even greater difficulty convincing the



medical establishment that their fatigue, muscle weakness and pain are related to childhood polio. These people have a history of polio, either documented by hospitals or by family records and stories, but there are many people who had polio and don't even know it. Members of all of these groups can and do experience the late effects of polio, as discussed further in **Appendix B**.

Data from the *Late Effects of Disability Clinic* in Western Australia suggests that the majority of polio clients are in the age range of 50 – 59 (44%), followed by 60 – 69 (24%). The number of clients accessing *Polio Services Victoria* has been increasing, and the mean age of new clients is now 48 years (2006), whilst in 2001 it was 69 years. This change in mean age is related to the increase in referrals of clients from a CALD background, with particular emphasis on clients from the Indian sub-continent and South East Asia. In 2006, 33% of new referrals for the service were migrants or refugees.

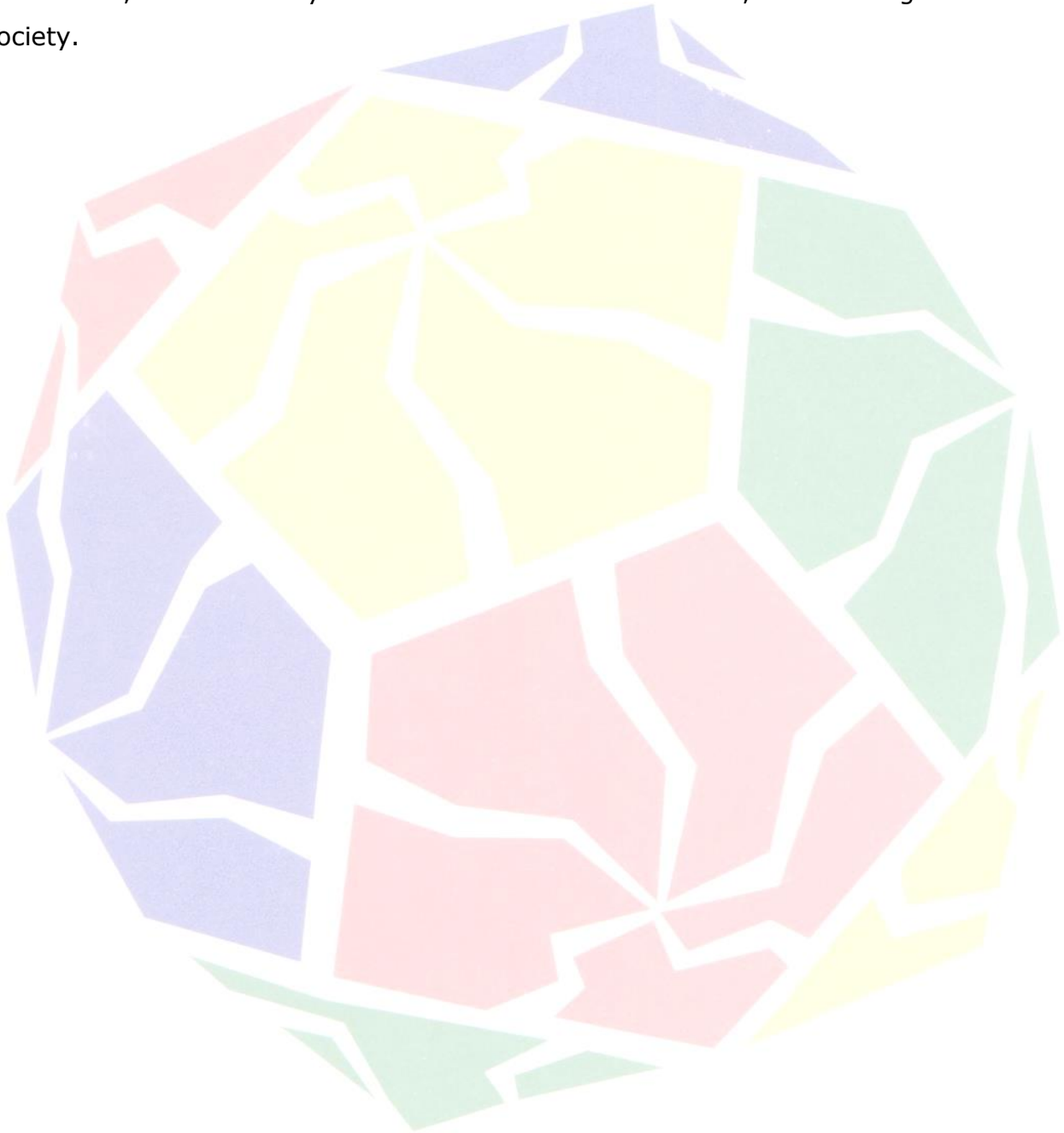
## Conclusion

The existing state Networks have been committed to supporting polio survivors for almost 20 years through the provision of information, education and support groups. These Networks were established by volunteers, and in most cases continue to operate as a result of the efforts of a number of dedicated, successful, and outcome oriented volunteers. However, these volunteers are predominantly polio survivors, and although they are committed to supporting the Networks they also must manage their own disability and health needs with very little support from the health system.

Polio Australia will draw on the considerable expertise in the existing state Networks to achieve success in the proposed national education program. Polio Australia will provide information, education and training to General Practitioners and other health professionals to improve the diagnosis and management of the late effects of polio. Polio Australia will also support the many thousands of polio survivors living in Australia, through the provision of relevant information and education.



The late effects of polio will become an increasing issue for communities around Australia as the population ages, and as the community diversifies with people from regions including the Indian sub-continent choosing Australia as their home. Polio Australia's education programs will ensure the quality of life of polio survivors is maintained, and that they continue in their role as valued, contributing members of society.





## Appendix A

### What is polio?

Polio (poliomyelitis, or infantile paralysis as it has also been called) is a viral disease that was common in the Western world until the early 1960s. Polio is caused by an enterovirus of which there are three distinct strains, and none of these strains provide cross-immunity to the others. Infection occurs through the faecal-oral route, through direct or indirect contact. Polio first came under notice in Australia at the end of the 19th century. There were two particularly large epidemic outbreaks in Australia, one in the late 1930s and early 1940s and the other about ten years later, but polio infections in fact occurred every year and the disease remained common into the early 1960s.

Paralytic polio is the most serious type of polio and causes paralysis through the virus invading the central nervous system, spinal cord and the brain. Problems associated with paralytic polio include weakness, paralysis, serious breathing problems, or death. The recovery from paralytic polio varies, but people who suffer paralysis from the infection have muscle weakness and related disability to a greater or lesser extent for the rest of their lives.

Residual complications include:

- muscle paresis and paralysis, which may result in skeletal deformities, joint contractures and movement disability;
- growth retardation of an affected limb(s);
- osteoporosis and subsequent fractures due to inactivity;
- pain from wear and tear due to abnormal body mechanics;
- compression neuropathy from the use of crutches, callipers or a wheelchair;
- respiratory insufficiency;
- intolerance to cold due to circulatory disturbances.



The diagnostic distinction between “paralytic” and “non-paralytic” polio was entirely arbitrary during the epidemics of the last century. In fact, the category of non-paralytic polio contained many patients with mild or temporary paralysis and with encephalitis, which occurs in people reaching the later stages of this illness. Modern studies indicate that overt paralysis in these people depends entirely on the percentage of spinal nerve cells destroyed. For damage to be visible as weakness or paralysis at least 50% to 60% of the nerves controlling muscular action must be damaged or destroyed.

Up to 40,000 people were diagnosed with paralytic polio in Australia from 1930 onwards. Incidence rates of between 10 and 20 cases of paralytic polio per 100,000 inhabitants each year were commonly experienced during epidemics. These figures must be increased 100-fold to obtain the estimated number of infected cases during the same time period (up to 4 million people), and they do not include people who contracted polio overseas and who have since entered Australia. Between 1930 and 1960 there were approximately 2,000 reported deaths due to acute polio. [Reference: Leboeuf C, *The Late Effects of Polio – Information for Health Care Providers*, Commonwealth Department of Community Services and Health 1990]

With the advent of the polio vaccines (Salk was introduced in Australia in 1956 and Sabin in 1966) and subsequent successful mass immunisation programs, new cases of the disease were eliminated in Australia as well as in all other developed countries.

Although acute poliomyelitis is a rare condition in Australia today, there are many tens of thousands of people who have been left with a wide range of disabilities, which restrict and impede the activities of their daily living. In addition, people who contracted both paralytic and non-paralytic polio are now experiencing the late effects of polio. Polio survivors across Australia are increasingly seeking information on managing the condition from poorly informed medical professionals who are ill-equipped to advise them. Comprehensive support services are few and far between.



## Appendix B

### The late effects of polio – some statistics

International researchers have broken down polio statistics as follows:

- In 100 cases of polio (both diagnosed and undiagnosed cases), only 1 person will have paralytic polio.
- Ten people will have non-paralytic polio.
- All of these people who were diagnosed with paralytic or non-paralytic polio will have some nervous system damage. This means they may develop the late effects of polio many years after contracting the virus.
- The remaining 89 people do not even know they had polio. The majority will have had no symptoms at all. Some had a fleeting stomach upset and may have felt slightly unwell, but none of these will have had nerve damage. However somewhere between 10 and 20 people will have had undiagnosed polio, possibly even paralytic polio. These people are all at risk of developing the late effects but will not be aware of the cause of their symptoms.

Therefore, survivors with less damage who may have had a minor illness, and some people who were asymptomatic can still present many years later with classic late effect symptoms.

Relating these figures to the Australian experience, it has been estimated that up to 40,000 people contracted paralytic polio in this country between 1930 and 1988. As noted above, these figures must be increased 100-fold to obtain the estimated number of infected cases during the same period (up to 4 million people). The figures do not include people who contracted polio overseas and who have since entered Australia. [Reference: Leboeuf C, *The Late Effects of Polio – Information for Health Care Providers*, Commonwealth Department of Community Services and Health 1990]

The Post-Polio Network (NSW) Inc has undertaken two research projects (1998 and 2006) to quantify the extent and impact of the late effects of polio on the lives of those who contracted the disease and on those who care for them. The 2006 research provides an unusual and valuable opportunity for comparison between two



studies which had many of the participants in common and in which many of the issues addressed were the same.

The Network's latest research report *Polio – The Living Legacy* was published in November 2007 and copies are available on request. Some major findings include:

- Almost all polio survivors experience the debilitating problems of muscle weakness (92%) and fatigue (89%).
- At least 64% report, in order of frequency, muscle pain, joint pain, sensitivity to cold, muscle atrophy, tendency to fall, sleep problems and muscle cramps.
- More than half of those surveyed experience muscle twitching and problems with finding words.
- Breathing difficulties, headaches, change in voice and swallowing difficulties were reported by between 37% and 43% of respondents.

While these conditions may be exacerbated by ageing, they are not directly age related as most difficulties are experienced across the full age range of participants, with younger respondents experiencing many problems equally, or even at a greater rate, than older participants, and sooner than would be considered to be the result of ageing in the general population. It is also apparent that many of these difficulties have increased over the ten years between surveys.

Research participants also provided information on a number of aspects of personal life including personal care; undertaking household tasks; reliance on family; mobility and transport; employment; exercise; and the use of aids and appliances.

The overall picture is of a group of people who have many physical limitations and many difficulties in managing daily life. At the same time, they have contributed greatly to Australian society – they have raised families, excelled in their chosen professions, and are now coping with their increasing disability with determination in the face of limited and fragmented services. Taking survivors and their families together, the number of people feeling the impact of the late effects of polio on their lives easily trebles from the number who actually contracted the disease. Across Australia, these people deserve information, support, and health and ancillary services from comprehensively educated and trained professionals.