



Proposal

Polio Australia A National Voice

representing
Polio Survivors in Australia



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 to represent the needs of polio survivors in Australia. It was recognised that this national body, 'Polio Australia', would require seed funding in order to create the organisation. Therefore, the Networks are seeking \$1 million over four years from the federal government to establish the organisation and to achieve a comprehensive set of outcomes for polio survivors, their families and carers, health professionals and the community. Prompt diagnosis and effective management of the late effects of polio 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 seed 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.



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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 voice for polio survivors, 'Polio Australia'.

This submission seeks funding to enable Polio Australia to fulfil its mandate of ensuring appropriate, adequate and consistent services are provided to polio survivors across the country and, in conjunction with the state Networks, putting in place educative programs for health professionals, polio survivors and the community.



Polio Australia – a national voice

The cost of establishment

\$1million dollars over 4 years is being requested to establish Polio Australia, and to provide adequate time to ensure the organisation becomes self sustaining. This request includes establishment funds, and salaries for an Executive Officer, a Senior Project Officer and a Project/Administrative Officer.

A comprehensive establishment and annual budget is given in Appendix A.

The vision

The Post-Polio Networks of Australia have been seeking sustainable solutions for supporting polio survivors for a number of years.

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. Subsequent to the conference, all state Networks have reaffirmed their commitment to the establishment of Polio Australia and letters of support are given in **Appendix B**. Synopses of the history and activities of each of the state Networks are provided in **Appendix C**.



Aims of Polio Australia

Polio Australia is currently being formally established and the following objectives for the national body have been identified:

- Facilitate and encourage the co-ordination and further development of activities within and between the state Networks.
- Employ designated staff to support the state Networks in their educative role.
- Develop consistent policy and procedures to support the state Networks.
- 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.
- Provide information, education and training to General Practitioners 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.
- Stimulate research into the late effects of polio.
- Support and promote polio immunisation at a national level, and provide assistance to the state Networks to do so at the local level.
- Advise governments on policy development and programs in relation to the late effects of polio.
- Secure permanent recurrent funding through national fundraising campaigns to support the mission of Polio Australia and of the state Networks.



A look at the late effects of polio

Polio (described in more detail in **Appendix D**) 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 E**.

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.

An aim of Polio Australia is to establish multi-disciplinary Polio Clinics in each state, based on the model already established in Victoria and Western Australia. **Appendix F** describes this best-practice approach to the management of the late effects of polio.

Conclusion

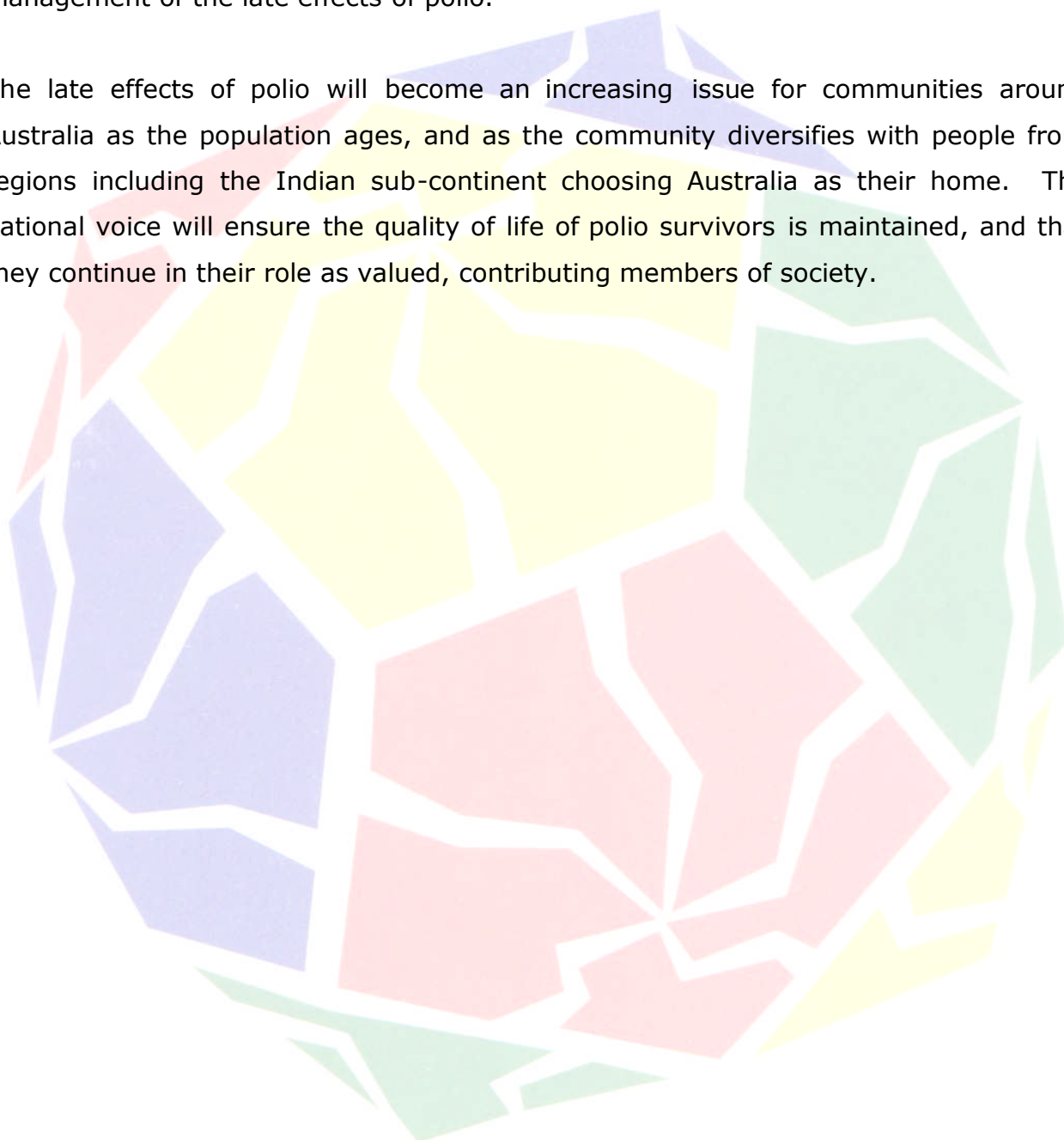
The existing state Networks have been committed to supporting polio survivors for almost 20 years through the provision of information, education and support groups. These Networks were established by volunteers, and in most cases continue to operate as a result of the efforts of a number of dedicated, 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 work with the Networks to achieve success through the employment of an Executive Officer, a Project Officer and a Project/Administrative Officer. The recruitment of these positions will ensure the aims of the Networks are



supported and developed. Polio Australia will support the many thousands of polio survivors living in Australia, through the provision of relevant information, education and health care. Polio Australia will also provide information, education and training to General Practitioners and other health professionals to improve the diagnosis and management of the late effects of polio.

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. The national voice 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

Polio Australia – establishment and annual budget

Establishment Costs Year 1	Amount	Notes
Vehicle	\$28,000	
Computers x 3	\$10,000	
Phones	\$2,000	Including mobiles
Office set up	\$18,000	Chairs, tables, photocopier, fax, printer etc
Resources	\$4,000	
Recruitment	\$1,500	Initial recruitment
Initial Training	\$3,000	
Legal Fees	\$5,000	Incorporation costs
Printing of education material	\$15,000	
TOTAL ESTABLISHMENT	\$86,500	

Annual Budget	Amount	Notes
Income Year 1		
Proposed Government Contribution	\$228,375	
Member fees	\$3,000	Levied on state Networks
TOTAL INCOME	\$231,375	
Expenditure Year 1		
Executive Officer	\$55,441	Above Award – 35 hours/week
Senior Project Officer	\$41,417	SACS Award Grade 4 year 1 – 35 hours/week
Project/Administrative Officer	\$34,915	SACS Award Grade 3 year 1 – 35 hours/week
Staff On Costs	\$19,372	Including super and workers compensation
Staff Training & Development	\$2,000	
Accommodation/Property	\$22,500	
Travel	\$10,000	
Marketing/Promotion	\$2,000	
Administration Costs	\$17,730	
Information/Education Sessions	\$12,000	
Consultancy	\$3,000	
Vehicle Running Costs	\$11,000	
TOTAL EXPENDITURE	\$231,375	

Proposed Government Funding over 4 years	Amount	Notes
Establishment Year 1	\$86,500	One-off set up
Costs Year 1	\$228,375	
Costs Year 2	\$228,375	Polio Australia will cover CPI increase
Costs Year 3	\$228,375	
Costs Year 4	\$228,375	
TOTAL FUNDING REQUEST	\$1,000,000	



Appendix B

Letters of support

All state Post-Polio Networks support the establishment and aims of Polio Australia.

Letters of support follow, from:

Post-Polio Network (NSW) Inc

Polio Network Victoria

Post Polio Network Western Australia

Post Polio Support Group of SA Inc

Post Polio Support Queensland

Post Polio Network – Tasmania Inc



POST - POLIO NETWORK (NSW) INC.

Supporting polio survivors and their families since 1989

Phone/Fax No: (02) 9663 2402
Email: president@post-polionetwork.org.au

PO Box 888 Kensington
NSW AUSTRALIA 1465

TO WHOM IT MAY CONCERN

I wish to advise that the Post-Polio Network (NSW) Inc was the initiator and organiser of the Polio Australasia Conference *Designing a Future* which was held in Sydney on 3 and 4 May 2007.

At this Conference the organisation to be known as Polio Australia was formally established with the full agreement and participation of the Post-Polio Network (NSW) Inc.

The Post-Polio Network (NSW) Inc will be represented on the Management Committee of Polio Australia and will provide delegates to attend and participate in Polio Australia meetings.

The Post-Polio Network (NSW) Inc wholeheartedly endorses the formation of Polio Australia and will abide by its Constitution.

Yours sincerely

Gillian Thomas
President

10 August 2007

23 August 2007

TO WHOM IT MAY CONCERN

The Polio Network, a service of ParaQuad Victoria, was represented at the "Polio Australasia" conference in March 2007, which deliberated the establishment of a national body representing polio survivors in Australia.

In principle, ParaQuad Victoria and its Polio Network service fully supports the establishment of "Polio Australia" as the national voice for the polio community, and will work together with the other state based polio networks to ensure the development of an appropriate service that meets the requirements of all key stakeholders.

We look forward to progressing the formation of this essential and long overdue organisation.



Peter Turner
Chief Executive Officer



poliowa

POST POLIO NETWORK of WA Inc

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Website: www.upnaway.com/poliowa Email: poliowa@upnaway.com

To: Mrs Gillian Thomas
President
PPN – NSW
PO Box 888
Kensington 1465

16/8/007

Dear Gillian

The Post Polio Network of WA would like to congratulate you for providing the impetus to formalise our umbrella polio group for the State Polio Groups of Australia. The Sydney Conference in May this year was enormously helpful in getting Polio Australia off to a secure footing as a coordinating mechanism for the individual efforts currently undertaken in each state by the various Post Polio organisations.

We look forward to progress in the official set up of this new body to assist polio survivors throughout Australia, with Constitution, Incorporation, funding grants etc.

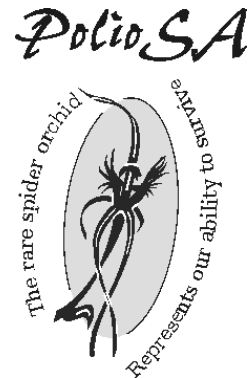
The united push for better access to necessary equipment, services and facilities, Polio Clinics, universal recognition of the Late Effects of Polio by governments and medical and allied health professionals is long overdue.

You have the full support of polio survivors in WA in establishing this new organisation that can benefit us all. Please keep us informed of any progress made.

Yours sincerely

Dr John Niblett FRACR FACHPM
President
Post Polio Network of WA Inc

**POST POLIO SUPPORT GROUP OF SA INC
11 BLACKS ROAD
GILLES PLAINS SA 5086**



TO WHOM IT MAY CONCERN

I wish to advise that representatives of the Post Polio Support Group of SA Inc attended the Polio Australasia Seminar which was held in Sydney on 3rd & 4th May, 2007.

At this seminar the organisation to be known as Polio Australia was formally established with the full agreement and participation of the Post Polio Support Group of SA Inc.

The Post Polio Support Group of SA Inc will provide delegates to attend and participate in Polio Australia meetings.

The Post Polio Support Group of SA Inc wholeheartedly endorses the formation of Polio Australia and will abide by its constitution.

Yours faithfully

Maria Harding

Maria Harding
Secretary

13th August, 2007

Spinal Injuries ASSOCIATION

August 17, 2007

To Whom It May Concern

The Spinal Injuries Association is the peak body representing people who are experiencing the late effects of polio in Queensland. The Association was represented at the "Post Polio Think Tank" hosted by the New South Wales Polio Network in Sydney in May which brought together Post Polio Support groups and networks from across Australia and New Zealand. Representatives from the Spinal Injuries Association included Frances Porter (Client Services Manager), Jo Toia (Member Networks Coordinator) and Dr Margaret Peel (Brisbane Post Polio Support Group member).

At the meeting there was unanimous support for the establishment of Polio Australia which includes the support groups and networks from across Australia. The Spinal Injuries Association supports the establishment of this federal group and looks forward to contributing to the success of Polio Australia.

Yours sincerely



Mark Henley
Chief Executive Officer

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(Secretary) Arthur L. Dobson – Phone (03) 63302961 Fax (03) 63302901 **Legana,**
(Chairperson) Grace Denison – Phone (03) 63261416 **Tas. 7277**

9th August, 2007

To whom it may concern.

re POLIO AUSTRALIA

I wish to advise that I, Arthur L. Dobson, along with Billie Thow and Keith Bennett, all being members of the Post Polio Network – Tasmania Incorporated, were present at the "Think Tank" titled "Polio Australasia – Designing A Future" held on 3rd and 4th May at the Northcott Society, 1 Fennell Street, Parramatta, NSW.

We each participated in the discussions regarding the formation of a national body to represent polio survivors in this country and agreed with the proposed formation of such a body preferably to be known as Polio Australia.

We agreed that each state organisation should have representation on the committee of this new organisation and I personally have agreed to assist in the development of a constitution for this new organisation.

This matter has been discussed with other members of the Post Polio Network – Tasmania Incorporated since May and all have agreed with decisions made at the "Think Tank".

We therefore confirm that the Post Polio Network – Tasmania Incorporated fully supports the formation of a national body preferably to be known as Polio Australia.

Yours sincerely,

Arthur L. Dobson

Arthur L. Dobson,
Honorary Secretary, on behalf of the members of,
Post Polio Network – Tasmania Incorporated,



Appendix C

State Networks – polio survivors helping themselves

In 1987 a number of Australians attended the *Fourth International Polio & Independent Living Conference* in St Louis USA. Some eight hundred people from around the world were present, all of them having symptoms of the late effects of polio. It seemed that too many people were experiencing difficulties for it all to be in their “imaginations”.

Those returning to Australia felt that attention must be drawn to the late effects of polio and that information should be provided to the many people who had contracted polio during the Australian epidemics.

In 1988 Professor Irving Zola, a member of the *International Polio Network* and himself a polio survivor, accepted an invitation to be keynote speaker at Australia's first post-polio seminar. This seminar was organised by participants at the 1987 USA Conference and was held in Sydney. The seminar provided the first opportunity in many years for people with polio to get together. It was discovered during the course of the day that most of those present were experiencing symptoms identified with the late effects of polio. One of the most important things that came out of the seminar was the feeling for so many attendees that at last they were no longer isolated from each other in their experiences. What a relief to know that “*I’m not the only one who has this after all*”.

The seminar inspired a great deal of media interest, including articles in the *Sydney Morning Herald* and coverage on ABC Radio National’s *Health Report*. As a result enquiries were received from across Australia and, over the next few years, a Network was established in each state.

(There are currently no Networks in the ACT or the Northern Territory. The NSW Network supports polio survivors in the ACT, and those in the Northern Territory access information through the nearby state Networks.)



New South Wales

The major recommendation from the 1988 Sydney seminar was that a Post-Polio Network be established in NSW with the following aims:

- Establishment of a support group for polio survivors.
- Establishment of an information base.
- Provision of up-to-date information on the late effects of polio to polio survivors and health professionals.
- Encouragement of research into the late effects of polio and their management.
- Organisation of information seminars on the late effects of polio.

A Working Committee was elected to pursue these and other recommendations from the seminar.

The Post-Polio Network (NSW) Inc was officially established in 1989 and is a voluntary, self-funded, self-help organisation, which is governed by a Management Committee whose members are predominantly polio survivors.

The NSW Network has achieved many positive outcomes since its inception, including hosting an international conference (1996). Currently the Network:

- Has around 1,000 members and 30 support groups.
- Produces a quarterly newsletter *Network News* with peer-reviewed articles.
- Holds quarterly information Seminars throughout the state.
- Maintains a comprehensive website which attracts and informs visitors from around the world.
- Distributes a quarterly *Information Bulletin* with information about services and products available to people with disabilities.
- Undertakes research into the extent and impact of polio's late effects.
- Stages Post-Polio Awareness Week each year.
- Supports and promotes polio immunisation campaigns.

Viability is an ongoing issue for the NSW Network which operates from membership fees and donations, with some assistance from Northcott Disability Services.



Victoria

Polio survivors from Victoria also attended the 1987 Conference in the USA. Concerned about the lack of support, resources and information for people in Australia, they brought back all the information that they could from the Conference. With support from the Paraplegic Association of Victoria (ParaQuad Victoria), a public meeting was held and 125 people attended. Subsequently, a polio survivors' network was established within the Paraplegic Association.

Initially, the network gathered and disseminated information to polio survivors, and brought people together to form self-help groups. Within the first year of operation in Victoria, 400 polio survivors had been contacted, a newsletter had been published, and a seminar organised which attracted participants from a number of states. Some of the outcomes and recommendations from the seminar were taken up with the Health Department.

Since that time, Polio Network Victoria has achieved a number of outcomes including:

- Development of geographically based support groups. There are currently 20 throughout the state.
- Development of an Advisory Group.
- A Health Professionals Symposium to inform the medical and allied health professionals about the needs of polio survivors.
- Running a series of seminars and forums.
- Developing a positive relationship with the Post Polio Advisory Unit established in 1991.

The aims of the Victorian Network are to:

- Provide current information on polio and its late effects, and on the availability of community services to people who have had polio, their families, carers and advocates.
- Assist in the formation and networking of community support groups for people who have had polio.
- Raise the awareness of issues affecting people who have had polio within the wider community.



- Promote immunisation as a means of polio prevention and eradication.
- Promote an awareness of the Network to potential users, community support groups, service providers and health professionals.

Western Australia

Post Polio Network Western Australia (PPNWA) was formed in August 1989 as a self-help group for polio survivors. The initial public meeting drew 230 people from all over Western Australia. PPNWA was initially supported by the Paraplegic-Quadriplegic Association of WA, and an affiliation with the organisation still exists. The organisation attained incorporation status and employed a Nurse Coordinator in 1992, through fundraising for the position. PPNWA receives no government funding.

The Network is governed by a Management Committee the majority of whom are polio survivors. The Nurse Coordinator remains as the only employee of the Network, and conducts clinics, fundraises, edits the newsletter and participates in research. Volunteers support the Nurse Coordinator in office work and administrative duties.

Since the Network's inception, around 2,000 polio survivors in WA have been contacted, and it is anticipated that there are perhaps another 1,000 polio survivors in WA who have not as yet registered with the Network.

In 2000 PPNWA was successful in persuading the WA Health Department to fund a "Late Effects of Disability" clinic at Royal Perth Rehabilitation Hospital; the major users of the clinic are polio survivors. This clinic provides a comprehensive muscle assessment, medical review and development of individually tailored exercise programs that are pool or gym based as desired by the patient. Regular reviews are undertaken and instant re-access to the clinic is possible if circumstances change (for example, injury).

South Australia

The Post Polio Support Group of SA Inc (Polio SA) is a volunteer operated organisation which provides information about the late effects of polio to members and the greater community, and provides a supportive network thorough consultations, referrals and social gatherings.



The Polio SA services include:

- Mutual support through group meetings
- Newsletters including local and international developments
- Counselling
- Advocacy
- Connecting people

Polio SA has about 300 members with around 25% being located in regional locations.

Queensland

In 1991, a group of people who had suffered polio and who were members of the Paraplegic and Quadriplegic Association of Qld (now called Spinal Injuries Association Qld Inc) identified the need for the formation of a support group. By that year information about people suffering new symptoms was starting to come to the fore. After an initial meeting support groups were formed throughout the state.

There are now more than 400 members accessing Post Polio Support Groups in:

- Cairns
- Townsville
- Sunshine Coast
- Brisbane
- Toowoomba
- Gold Coast

These groups offer support and shared experiences in dealing with the late effects of polio. Services include:

- Regular meetings
- Presentations on health topics identified by members
- Social interaction
- Raising awareness
- Post-Polio Awareness Week



In addition to the support groups, Spinal Injuries Association continues to provide support for people experiencing the late effects of polio by:

- The ongoing development of lists of health care professionals by districts in Queensland who are known to have a knowledge of the late effects.
- Supporting Post Polio Support Groups throughout the state.
- Lobbying for the establishment of relevant health services.
- Coordinating state-wide Post Polio Awareness Week activities.
- Raising awareness of post polio in the community.

Tasmania

The Post Polio Network – Tasmania Inc was established in May 1998 when a need was seen for a state-wide polio network similar to those established in other states of Australia. Prior to this, there had been an organisation known as Tas Polio Support which wound up when the founder could not continue running the organisation.

The current Network was established with the aim of providing relevant and accessible information, referral and support services to people who have had polio, their families, carers and advocates.

The membership is currently around 120 with ongoing inquiries bringing in new members to replace those who pass away or leave for other reasons. Around half of the members regularly attend support groups throughout the state. The main method of communication with members is by newsletter, *Tas Polio News*, which contains helpful advice and general interest information for the readers. The Network also raises awareness of post polio by involvement in the community. The Network receives a small annual grant from St Giles, but aside from that it is difficult to resource the group.



Appendix D

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 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, are increasingly seeking information on managing the condition, and are in need of comprehensive support services.



Appendix E

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 2006 research report *Polio – The Living Legacy* is currently in press. 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 and requiring information, support, and health and ancillary services easily trebles from the number who actually contracted the disease.



Appendix F

A best-practice approach to the management of the late effects of polio

There is no test that diagnoses the late effects of polio. A diagnosis is based on medical history, medical assessment and identifiable symptoms. In addition to this, there are no specific treatments for the late effects and best practice in management for the condition is evolving. However, symptoms may be controlled or improved by:

- Avoiding physical over-exertion and stress.
- Modifying activities of daily living to conserve energy.
- Keeping warm and avoiding exposure to cold temperatures.
- Using equipment including callipers, braces, walking sticks and electric scooters to promote mobility and manage pain.
- Ensuring that exercise is tailored to the individual, is not painful and does not cause fatigue.
- Managing weight as much as is possible with an often-imposed sedentary lifestyle.

It is recommended that a person experiencing the late effects of polio has access to a range of medical and allied health professionals to form an interdisciplinary approach to management. Management needs to be symptom specific, with input potentially from the following:

- Rehabilitation Specialist – to assess the range of needs and refer to appropriate other health professionals.
- Physiotherapist – for weakness, pain and mobility problems.
- Respiratory Therapist – for breathing issues.
- Orthotist – for braces, callipers, orthotics, trunk support and specialist footwear.
- Occupational Therapist – to prescribe equipment, modifications and aids.
- Speech Pathologist – for issues related to speaking or swallowing.
- Pain Clinic – to manage chronic pain.



- Psychologist – to support people with anxiety and depression.
- Dietician – to manage weight gain as a result of an inability to do vigorous exercise.

A long term goal of Polio Australia is to support polio survivors to meet their health care needs through the establishment of a Polio Clinic in each state. The development of a comprehensive evaluation and management program is essential for polio survivors to ensure that post-polio symptoms are addressed and the progression of symptoms is reduced. Even if the survivor may not yet be exhibiting late onset problems, comprehensive evaluation and the development of a management plan that addresses optimal health and well-being can be beneficial in minimising the impact of future problems.

In Victoria and Western Australia there are clinics which provide specialist assessment and care planning for people with the late effects of polio. However, in the other states and territories in Australia, there is no specialist medical or healthcare support. Polio survivors need to search until they find professionals who have an understanding of the symptoms and management of the late effects, or who are sympathetic to the needs of polio survivors. Many polio survivors are subjected to statements such as 'post polio does not exist' while they search for support. Many polio survivors are subject to inappropriate treatment and/or care regimes in hospital because not enough is known about the limitations imposed by the late effects of polio.

Finding appropriate support will be a result of the following: referral from another polio survivor, luck, or a lengthy and potentially costly process of search and elimination. This process has to be repeated for each area of need (that is, physiotherapy, occupational therapy etc). Therefore, polio survivors in all but 2 states are required to manage their own health needs, by seeking appropriate support and coordinating all care. This is not an effective model of care due to the pressure it places on the polio survivors to be informed, educated and an advocate for their needs, whilst receiving fragmented support from professionals who are working in isolation.



In addition, this has significant cost implications on the community as polio survivors spend years searching for a diagnosis and seeking effective treatment strategies. While searching for support, polio survivors access a range of doctors and are subjected to numerous tests, all of which costs the health system vast amounts of money.

Due to the complex nature of the late effects of polio, it is often necessary to refer polio survivors to a range of health professionals who have specialist skills and knowledge that can assist the survivors to manage their often disabling symptoms.

This is the model which is currently operating at *Polio Services Victoria*, and through the *Late Effects of Disability Clinic* in Western Australia. These clinics provide a holistic approach to meeting the needs of polio survivors through provision of support at the clinic, or outreach support. The model has proven to be an effective way of supporting polio survivors, however resources are limited and demand exceeds the availability of support. The established clinics could provide the framework for the development of clinics in other states. These clinics would facilitate the professional development of the staff providing the support, which would in turn contribute to the improved overall health and well-being of polio survivors.