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POLIO AUSTRALIA INCORPORATED

Representing polio survivors throughout Australia

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Polio Australia

Leading Polio Services into the Future



L-R: Neil von Schill (Treasurer), Mary-ann Liethof (National Program Manager), Dr John Tierney (National Patron), Gillian Thomas (President)

Update prepared for the

~ Patrons and Friends of Polio Survivors ~

Parliament House
Canberra ACT

Wednesday 22nd June 2011

In the Beginning



- In the 1980s, conferences discussing the emergence of “Post Polio Syndrome” commenced in the USA
- A number of Australian polio survivors attended in 1987 and brought back this vital information
- Consequently, Polio ‘Networks’ were independently established in each state

Watching it Grow

- State Networks have been proactive in a number of areas including developing support groups, disseminating information, and arranging seminars and conferences



Peer Support

- For many of Australia’s polio survivors, the late effects of polio cause significant and ongoing problems for which there is minimal specialist knowledge and support available
- Peer support and shared information has greatly assisted polio survivors to better understand and manage many of the symptoms associated with the late effects of polio



Designing a Future

- 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
- This would be done through centralised information provision and in the development and delivery of comprehensive education and training programs to the polio community and their health professionals



State Polio Network Delegates

Getting Started

- Polio Australia became incorporated in 2008
- Following a small philanthropic grant received in 2009, the Committee of Management was able to employ a part time worker and set up an office in Kew, Victoria in Jan 2010
- By April 2010, the first Australian Polio Health and Wellness Retreat was held in NSW



Federal Parliamentary Patrons and Friends



Greg Hunt, MP (Lib/Vic) - Jill Hall, MP (ALP/NSW) - Catherine King, MP (ALP/Vic) - Mark Coulton, MP (Nat/NSW)

- To achieve its goals, delegates from Polio Australia have visited policy and decision makers in Canberra on five separate occasions with a fully costed 4 year funding proposal (see *Appendix A*)
- We are privileged to have the support of four bi-partisan “Parliamentary Patrons” and a Parliamentary “Friends of Polio Survivors” group
- Despite these efforts, to date no financial support has been forthcoming

The Next Three Years



Just as the one year grant was running out The Balnaves Foundation offered to fund Polio Australia to employ a full-time National Program Manager for three years commencing January 2011

Sitting (L to R): Neil von Schill (Treasurer), Gillian Thomas (President)

Standing (L to R): Mary-ann Liethof (National Program Manager), Hamish Balnaves, Neil Balnaves, Brad McIntosh (Trustees)

“Polio: The Next Wave” Study

- With support from The Balnaves Foundation, Polio Australia is commissioning a much needed study into the prevalence and incidence of polio in Australia. A second component of the study will target quantifying the economic, social and public health burden of the late effects of polio in Australia.
- **Polio Australia is seeking matching funding of \$50,000 to complete and disseminate this comprehensive study.**
- Overall, the study aims to answer the following questions:
 - how many polio survivors are there in Australia today?
 - how many are likely to be affected by the late effects?
 - what is the cost to government and the community of not diagnosing, treating and managing the late effects appropriately?
 - what are the savings/benefit to government by putting appropriate services in place now?
- It is hoped the study will assist Polio Australia to attract Federal government program funding to enable the provision, in conjunction with health professionals, of long-overdue support and services to Australia’s tens of thousands of polio survivors.

Australian Polio Register

- Polio Australia encourages every polio survivor living in Australia (whether polio was contracted in Australia or overseas) to join the Australian Polio Register
- It is recognised that our strength lies in our numbers so every opportunity is taken to encourage people to sign up
- This can be done 'on line' on Polio Australia's website or completed by hand and posted back to Polio Australia
- To date we have had approximately 1,000 registrations after only a few months

Clinical Advisory Group



L-R: Darren Pereira (Orthotist/Vic) – Melissa McConaghy (Physiotherapist/NSW) – Dr Wilbur Chan (Rehab Specialist/Qld) – Dr Mary Westbrook (Psychologist/NSW) – G. Jegasothy (Physiotherapist/WA) – Dr Nigel Quadros (Rehab Specialist/SA) – Phil Ladlow (Physiotherapist/Tas) – Dr Stephen de Graaff (Rehab Specialist/Vic) – Dr Diane Bull (Neuro-Psychologist/NSW) – Prof Robert Booy (Infectious Diseases Specialist and Paediatrician/NSW) – Natasha Layton (Occupational Therapist/Vic) (missing: Dr Peter Nolan, Rehab Specialist/Qld and Anne Duncan, Outreach Worker, Victorian Respiratory Support Service)

- To help achieve its Mission, Polio Australia has established a Clinical Advisory Group (CAG) comprising open-minded health care professionals who are experts in their field and have knowledge about polio and its late effects (*see Appendix B*)
- The group composition represents health care professionals from every state and specialising in diverse areas such as immunisation, rehabilitation, physiotherapy, orthotics, psychology, respiratory and research
- **Polio Australia is now seeking funding of \$393,350 over the next 3 years to support the Clinical Advisory Group in the first stage of a project to develop and distribute “Best Practice Recommendations” for Health Professionals working with polio survivors** (*see Appendix C*)

Accomplishments to Date

January 2010	Established office in Kew, Victoria
March 2010	Launched “Parliamentary Friends of Polio Survivors” at Parliament House
April 2010	Facilitated Australia’s first Polio Health & Wellness Retreat (NSW)
September 2010	Developed and launched website
September 2010	Launched “Australian Polio Register”
October 2010	Wear Orange for Polio Day Awareness Campaign
October 2010	Launched Polio Australia’s monthly e-Bulletin
February 2011	Held first Clinical Advisory Group (CAG) teleconference
April 2011	Facilitated second Retreat (VIC)
Current	Organising 2012 Retreat in QLD * Polio: The Second Wave Study *
June 2011	Launching Polio Australia’s quarterly e-Newsletter
August 2011	Attending European Post Polio Conference to deliver oral presentation on Australia’s Retreats
October 2011	Polio Awareness Campaign (Wear Orange!) *
Ongoing	Working with CAG to develop Best Practice Recommendations for Health Professionals *

*** Funding Required**

Polio Australia's Vision

Polio Australia’s vision is to 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.

www.polioaustralia.org.au / office@polioaustralia.org.au



Participants at the 2011 Polio Health and Wellness Retreat

Polio Australia: Leading Polio Services into the Future

Overall Operational Budget

Year One

Website development, production and promotion ⁽¹⁾	30,000
Information Pack development, production and distribution	40,000
Chronic Condition Self-Management Education program development ⁽²⁾	200,000
CME & CPD Podcast film development and production for GP's & AHP's ⁽³⁾	300,000
Research Project & Report ⁽⁴⁾	120,000
Development of media campaign for Polio Awareness	200,000
Associated administrative functions	200,000
Total	1,090,000

⁽¹⁾ Achieved

⁽²⁾ Partially achieved: 3 Day Residential Health and Wellness Programs run in NSW and Vic

⁽³⁾ First stage as per 'Detailed Budget' in *Appendix C*

⁽⁴⁾ Partial funding through The Balnaves Foundation

Year Two

Website maintenance and promotion	20,000
Chronic Condition Self-Management Education facilitation across states	800,000
CME & CPD Podcast film distribution and promotion ⁽³⁾	200,000
Polio Awareness campaigns	300,000
Professional Partnership Development	200,000
Associated administrative functions	300,000
Total	1,820,000

Year Three

Website maintenance and promotion	30,000
Chronic Condition Self-Management Education facilitation across states	900,000
CME & CPD Podcast film assessment and review ⁽³⁾	50,000
Polio Awareness campaigns	500,000
Professional Partnership Development	400,000
Associated administrative functions	500,000
Total	2,380,000

Year Four

Polio Australia Projects Survey development, distribution and evaluation	30,000
Website maintenance and promotion	20,000
Chronic Condition Self-Management Education facilitation across states	1,200,000
Polio Awareness campaigns	800,000
Professional Partnership development	800,000
Associated administrative functions	800,000
Total	3,650,000

TOTAL OVER 4 YEARS

\$8,940,000

Current Members of the Polio Australia *Clinical Advisory Group***Professor Robert Booy**

Head of Clinical Research
National Centre for Immunisation Research &
Surveillance
New South Wales

Dr Diane Bull

Psychologist & Conjoint Senior Lecturer / Director
The University Of Newcastle / forethought
consultancy group
New South Wales

Dr Wilbur Chan

Rehabilitation Physician/Pain Medicine Specialist
Division of Rehabilitation
Princess Alexandra Hospital
Queensland

Anne Duncan

Outreach Coordinator
Victorian Respiratory Support Service
Heidelberg Repatriation Hospital
Victoria

Dr Stephen de Graaff

Rehabilitation Specialist & Director of Pain
Services
Epworth Rehabilitation
Victoria

(Jega) Gnanaletchumy Jegasothy

Senior Physiotherapist
Late Effects of Disability Clinic
Royal Perth Hospital
Western Australia

Phil Ladlow

Neuro Physiotherapist
Allcare Physiotherapy
Tasmania

Natasha Layton

Occupational Therapist
PhD studies at School of Health and Social
Development and School of Health Economics
Deakin University
Victoria

Melissa McConaghy

Physiotherapist & Practice Principal
Mobile Rehab Innovations & Advance Rehab
Centre
New South Wales

Dr Peter Nolan

Clinical Associate Professor of Medicine
Rural Clinical School, University of Queensland
Queensland

Dr Nigel Quadros

Rehabilitation Specialist & Director of
Rehabilitation Services
The Queen Elizabeth Hospital
South Australia

Darren Pereira

Principal Orthotist & Director
NeuroMuscular Orthotics and Mobile Rehab
Innovations & Advance Rehab Centre
Victoria & New South Wales

Dr Mary Westbrook

Psychologist & Conjoint Professor
University of NSW
New South Wales

Polio Australia has enlisted the expertise of a multi-disciplinary panel of health professionals working together as a Clinical Advisory Group to develop criteria for Best Practices in Diagnosis and Management for people experiencing LEOP. With adequate financial resources, we would anticipate this work to roll out over a 3 year period.

Standardised quality information and service provision across Australia, incorporating appropriate diagnosis and management of the Late Effects of Polio, will ensure that polio survivors have access to appropriate health care and the support required to maintain independence and make informed lifestyle choices. The Clinical Advisory Group's work will provide a framework for informing health professionals who will, in turn, go on to educate their polio patients in the comprehensive set of management strategies suitable for their complex condition. This intervention will assist in keeping people out of acute care facilities as the result of imprudent practices, thereby reducing healthcare costs.

Effective diagnosis and 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.

Over a three year period in this national project, the Clinical Advisory Group will contribute to a comprehensive set of best practice diagnosis and management Best Practice Recommendations for a range of health professionals, as well as Fact Sheets for polio survivors who are seeking knowledge and direction on how to manage their condition. Similar work has not been previously undertaken in Australia.

This work is a bilateral approach to both upskilling the health professional and assisting in the facilitation of self-management for their polio patients. These Recommendations will be based on well researched and trialled strategies and standardised for use in clinical settings across Australia. These interventions are designed to ensure polio patients have access to appropriate health care which will support them in maintaining independence in the community, and reduce the incidence of admissions into the acute care system.

These Recommendations and Fact Sheets will be developed and made available in a range of formats such as: web based tools, the production of three instructional videos, and articles and advertisements in discipline-specific professional journals. Development of the Recommendations and Fact Sheets by their peers will facilitate their acceptance by the medical community and health professionals.

It is also intended that community input is drawn from an annual focus group meeting of polio survivors to ensure the target patients are fully cognisant of the work and its implications for clinical intervention. It is anticipated to hold the three focus group meetings in different states.

The projected outcomes of the three year project are:

- Video production for professional and patient instruction:
 - Assessment and diagnosis for health professionals
 - Exercise Recommendations for physiotherapists
 - Self management strategies for polio survivors
- Establishment of an instructional website for health professionals specifically for the management of the Late Effects of Polio, incorporating the Recommendations, videos, and patient Fact Sheets
- Professional production and distribution of Best Practice Recommendations for health professionals on:
 - Rehabilitation: Diagnosis and Management Strategies
 - Physiotherapy
 - Occupational Therapy
 - Respiratory / Sleep Therapy
 - Speech Therapy
 - Psychology
 - Orthotics
 - Acute Care / Hospital Admission Considerations
 - Drug Therapy
- Professional production and distribution of Fact Sheets for patients in the above health disciplines, plus:
 - The Late Effects of Polio: Self-Management Strategies
 - Nutrition
 - Complementary Therapies
- Articles and advertisements in professional journals for all of the relevant health disciplines listed above

Detailed Budget

Year 1

Item	Detail	Cost (no GST)
Staff Salary (incl on costs)	Project Officer 0.5 @ \$26.71 ph	\$30,000
Project Costs	Focus Group / Participant Costs	\$1,200
	Travel	500
	Postage / Stationery	500
	Publicity	500
	Venue Hire	500
	Printing	500
	Audit	500
Clinical Advisory Group	Teleconferences: 3 x \$250	\$750
	Face to Face Meeting x 20 participants:	
	• Flights and other transport	3,000
	• Accommodation	4,000
	• Venue and meals	2,000
Video Production	<i>"Assessment & Diagnosis for Health Professionals"</i>	\$40,000
Website Development	Instructional and Management Specific	\$20,000
Development of Recommendations for Health Professionals	Desk Top Publishing: 3 x \$1,000	\$3,000
	• Rehabilitation: Diagnosis and Management Strategies	
	• Physiotherapy	
	• Occupational Therapy	
Production of Fact Sheets for patients	Desk Top Publishing: 4 x \$1,000	\$4,000
	• The Late Effects of Polio:	
	• Self-Management Strategies	
	• Physiotherapy	
	• Occupational Therapy	
	• Respiratory / Sleep Therapy	
Publicity	Advertisements in three Professional Journals: \$1,500 per advert x 3 editions	\$13,500
Printing & Distribution of Published Materials	5,000 copies of each Recommendations and Fact Sheet x 7	\$20,000
	TOTAL	\$144,450

Year 2

Item	Detail	Cost (no GST)
Staff Salary (incl on costs)	Project Officer 0.5 @ \$26.71 ph	\$30,000
Project Costs	Focus Group / Participant Costs	\$1,200
	Travel	500
	Postage / Stationery	500
	Publicity	500
	Venue Hire	500
	Printing	500
	Audit	500
Clinical Advisory Group	Teleconferences: 3 x \$250	\$750
	Face to Face Meeting x 20 participants:	
	• Flights and other transport	3,000
	• Accommodation	4,000
	• Venue and meals	2,000
Video Production	<i>"Exercise Recommendations for Physiotherapists"</i>	\$40,000

Website	Hosting & Maintenance	\$1,500
Development of Recommendations for Health Professionals	Desk Top Publishing: 3 x \$1,000 <ul style="list-style-type: none"> • Respiratory / Sleep Therapy • Speech Therapy • Psychology 	\$3,000
Production of Fact Sheets for patients	Desk Top Publishing: 4 x \$1,000 <ul style="list-style-type: none"> • Speech Therapy • Psychology • Orthotics • Hospital Admissions 	\$4,000
Publicity	Advertisements in three Professional Journals: \$1,500 per advert x 3 editions	\$13,500
Printing & Distribution of Published Materials	5,000 copies of each Recommendations and Fact Sheet x 7	\$20,000
	TOTAL	\$125,950

Year 3

Item	Detail	Cost (no GST)
Staff Salary (incl on costs)	Project Officer 0.5 @ \$26.71 ph	\$30,000
Project Costs	Focus Group / Participant Costs Travel Postage / Stationery Publicity Venue Hire Printing Audit	\$1,200 500 500 500 500 500 500
Clinical Advisory Group	Teleconferences: 3 x \$250 Face to Face Meeting x 20 participants: <ul style="list-style-type: none"> • Flights and other transport • Accommodation • Venue and meals 	\$750 3,000 4,000 2,000
Video Production	<i>"Self Management Strategies for Polio Survivors"</i>	\$40,000
Website	Hosting & Maintenance	\$1,500
Development of Recommendations for Health Professionals	Desk Top Publishing: 3 x \$1,000 <ul style="list-style-type: none"> • Orthotics • Acute Care • Drug Therapy 	\$3,000
Production of Fact Sheets for patients	Desk Top Publishing: 3 x \$1,000 <ul style="list-style-type: none"> • Drug Therapy • Nutrition • Complementary Therapies 	\$3,000
Publicity	Advertisements in three Professional Journals: \$1,500 per advert x 3 editions	\$13,500
Printing & Distribution of Published Materials	5,000 copies of each Recommendations and Fact Sheet x 6	\$18,000
	TOTAL	\$122,950

3 year Total: \$393,350