

AUSTRALIA'S POLIO CHALLENGE IN 2012 AND BEYOND



POLIO AUSTRALIA INCORPORATED
Representing polio survivors throughout Australia

POLIO IN AUSTRALIA ...

- During the 20th Century poliomyelitis (polio) was a commonly contracted disease with frequent epidemics. Huge numbers caught polio. These may be categorised as follows:
 - 89% were unaware of infection or were affected minimally short-term and were not expected to be affected long-term
 - 10% appeared to recover short-term with no obvious resultant disability
 - 1% did not recover short-term and were left with varying degrees of paralysis (*minimal up to iron lung*)
 - 0.1% died due to respiratory involvement



POLIO AUSTRALIA INCORPORATED
Representing polio survivors throughout Australia

PARALYTIC POLIO ...

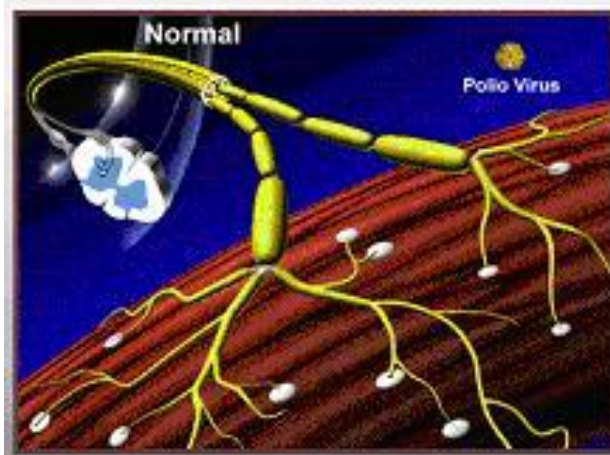
- 1% of polio survivors did not recover short-term and were left with varying degrees of paralysis – they are referred to as having contracted “paralytic polio”
- Between the 1930’s and 1960’s, 40,000 Australians contracted paralytic polio
- The same polio virus (3 strains) causes all categories of polio – “paralytic” polio is not caused by a “special” type of polio virus
- Some of the discussion about polio is confusing because the term “polio” is used when referring to only “paralytic polio” – the 40,000 paralytic polio cases represent only 1% of the actual polio numbers

RECOVERY FROM PARALYSIS ...

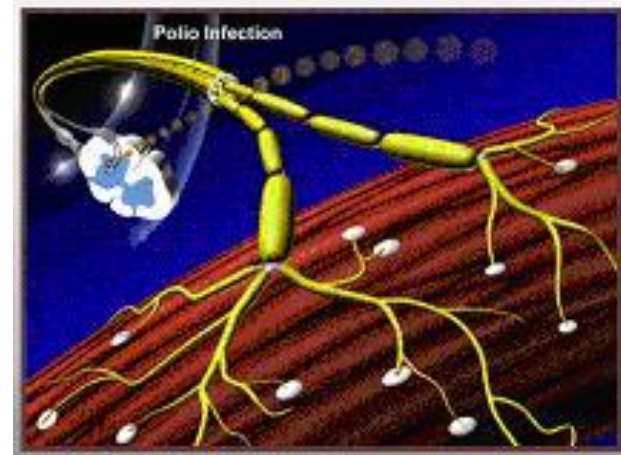
- While some polio patients appeared to recover from initial paralysis (diagnosis was probably “non-paralytic” polio), in reality, they still had neurological impairment.
- This is because paralysis is only visible when 50%+ motor neurons are killed or damaged
- In addition, muscle weakness may not be perceived if the weakness is balanced (eg weakness affects both legs)

POLIO VIRUS DAMAGE ...

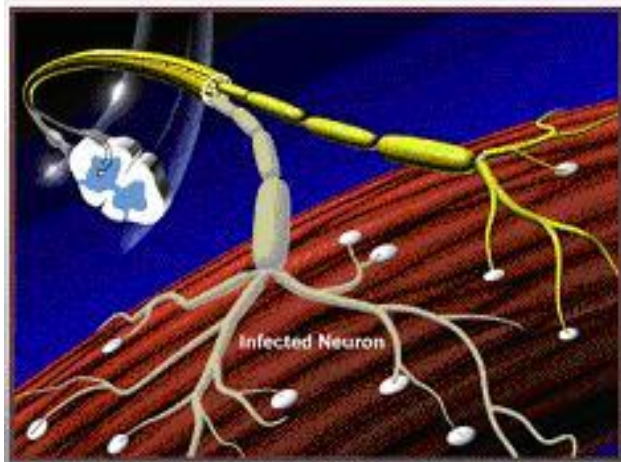
1



2



3



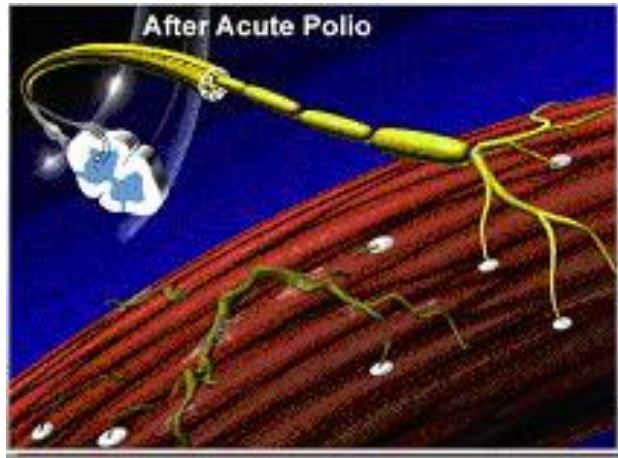
4



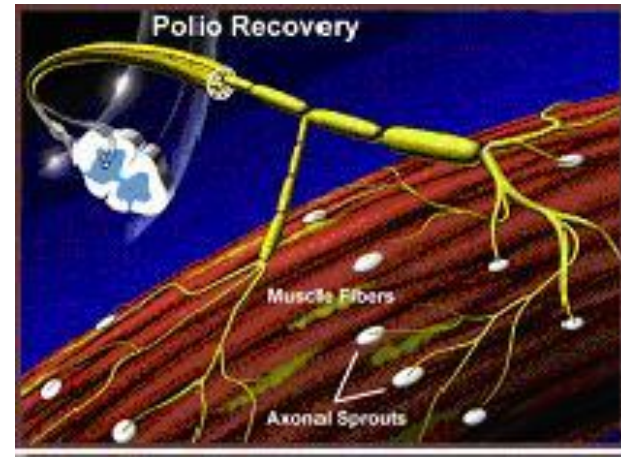
POLIO AUSTRALIA INCORPORATED
Representing polio survivors throughout Australia

RECOVERY FROM DAMAGE ...

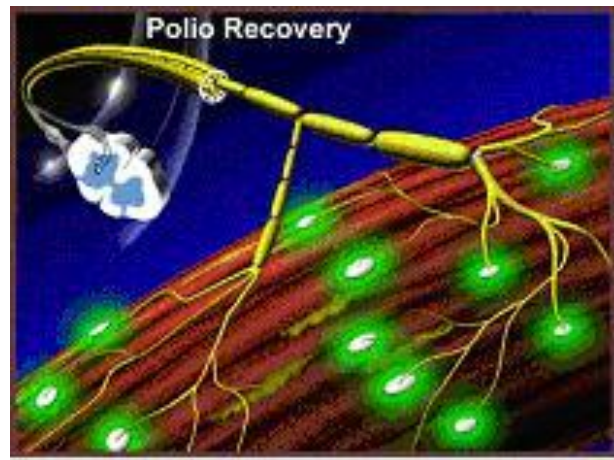
1



2



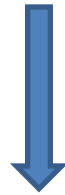
3



POLIO AUSTRALIA INCORPORATED
Representing polio survivors throughout Australia

LATE EFFECTS OF POLIO ...

Polio Survivor with
New Symptoms
(Late Effects of Polio - LEOP)



Biomechanical
Symptoms

+

Neurological
Symptoms
(Post-Polio Syndrome - PPS)

LATE EFFECTS OF POLIO (CONT'D) ...

○ **Biomechanical Symptoms**

Symptoms which would be normally expected to occur with time, due to biomechanical disadvantage from long-standing weakness which may be exacerbated by bodily asymmetry caused by polio, e.g.

- muscle and joint pain
- fatigue
- osteoporosis
- arthritis
- scoliosis/kyphosis
- increase in falls
- weight gain
- pronounced age-related weakness

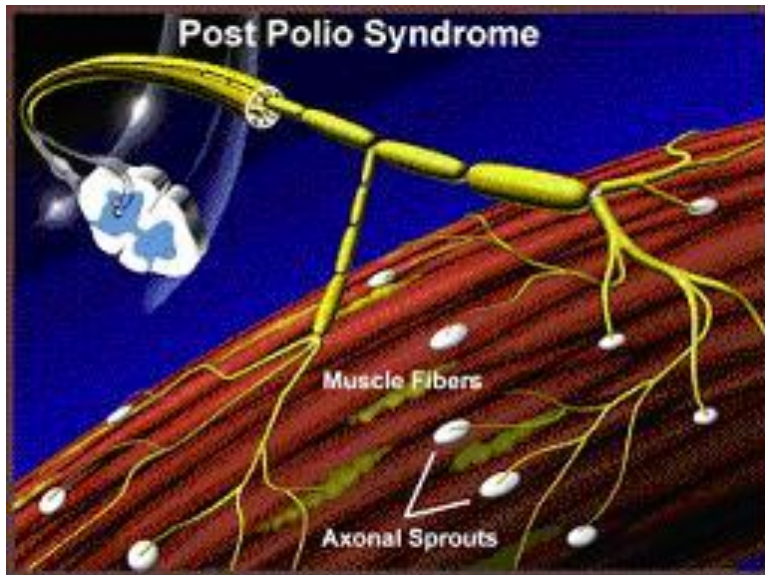
LATE EFFECTS OF POLIO (CONT'D) ...

○ **Neurological Symptoms (PPS)**

An otherwise unexplained constellation of symptoms in a patient and may include:

- new muscle weakness
- muscle and joint pain
- fatigue unrelated to activity
- new muscle wasting/atrophy
- heat or cold intolerance
- swallowing, breathing or sleep disturbance
- muscle twitching/fasciculation

POST-POLIO SYNDROME ...



POLIO AUSTRALIA INCORPORATED
Representing polio survivors throughout Australia

WHO IS AFFECTED BY LEOP/PPS? ...

- “It should be absolutely understood that patients who were told that they had ‘non-paralytic’ polio did, in reality, have polio, which affected their anterior horn cells. Now, 30 to 40 years later, these patients are potentially subject to all of the vagaries and insults to the body that affect other persons with postpolio syndrome.”

*A Clarification of “Nonparalytic” Polio
Johnson, Ernest W MD*

American Journal of Physical Medicine, Vol. 79(1), Jan/Feb 2000

- “Asserting that a history of paralytic polio is required for a history of PPS effectively, and incorrectly, says that no neurologic damage was done during acute nonparalytic polio.”

*Late Functional Loss in Nonparalytic Polio
Falconer, Marcia PhD; Bollenbach, Edward MA*

American Journal of Physical Medicine, Vol. 79(1), Jan/Feb 2000

WHO IS AFFECTED BY LEOP/PPS? (CONT'D) ...

- “PPS must be considered in the differential diagnosis of individuals with unexplained fatigue and weakness ... regardless of whether they report a prior history of paralytic polio”

Late Functional Loss in Nonparalytic Polio
Halstead, Lauro S. MD; Silver, Julie K.

American Journal of Physical Medicine, Vol. 79(1), Jan/Feb 2000

- Some related references:

- Ramlow J, Alexander M, LaPorte R, et al: Epidemiology of the post-polio syndrome. *Am J Epidemiol* 1992;136:769-86
- Nee L, Dambrosia J, Bern R, et al: Post-polio syndrome in twins and their siblings: evidence that post-polio syndrome can develop in patients with nonparalytic polio. *Ann NY Acad Sci* 1995;378-80
- Bruno RL: Paralytic vs. “Nonparalytic” Polio: Distinction Without a Difference? *Amer J Phys Med* 2000;79(1):4-12

RESEARCH ...

- In reviewing the evidence for this report, the committee recognized that there remain significant gaps in knowledge and understanding of the epidemiology, pathogenesis, diagnosis and optimal management of PPS, all of which need intensified research.

*2000 March of Dimes International Conference on Post-Polio Syndrome
– Identifying Best Practices in Diagnosis & Care*

- Due to insufficient good quality data and lack of randomised studies it is impossible to draw definite conclusions on the effectiveness of interventions for PPS. Results indicate that IVIG, lamotrigine, muscle strengthening exercises and static magnetic fields may be beneficial but need further investigation.

*2011 The Cochrane Collaboration
- Treatment for postpolio syndrome (Review)*



POLIO AUSTRALIA INCORPORATED
Representing polio survivors throughout Australia

RESEARCH (CONT'D) . . .

- The most promising research area to the cause of post polio syndrome focuses on the role of inflammatory factors that may be related to persistence of poliovirus fragments in the genome. Based on this, intravenous immunoglobulines may be beneficial to arrest or reduce the loss in strength and functional decline due to post polio syndrome.
- A recent Cochrane review concluded that the evidence for both pharmacological and rehabilitation interventions are insufficient and guidelines are based on limited levels of evidence.
- Therefore, high quality research of the effectiveness of pharmacological and rehabilitation interventions are needed, including cost-effectiveness evaluations to facilitate implementation in health care systems.
- Research interest needs to increase. Although research is being conducted in this area, the number of intervention studies in progress is scarce. Trial registries mention only one randomized study of rehabilitation interventions including health-cost evaluation.
- Research is hampered by little research interest, based on the false notion that post-polio syndrome is irrelevant because polio is a disease of the past, and, as for many orphan diseases, by funding barriers to execute pharmacological studies.

*2011 Conference Post Polio Syndrome – A Challenge of Today
- Summary by Dr. Frans Nollet, chairman of the scientific committee*



POLIO AUSTRALIA INCORPORATED
Representing polio survivors throughout Australia

IMPACT OF THE LEOP ...

○ At Home

"My biggest problem at the moment is difficulty using my hands which has never been a problem before – can't sew any more for instance; writing etc difficult – even typing. This is great stress!"

"Do not vacuum – too fatiguing and dangerous; meals: usually ask for help; supermarket: prefer help – too fatiguing and dangerous."

"Gardening, shopping, laundry, housework are hard to fit in when I have to rest periodically and pace myself in physical activities throughout the day. Entertaining and mixing socially can be very tiring."

IMPACT OF THE LEOP (CONT'D) ...

- Family and Personal Relationships

"My husband previously minimised my polio issues – he now realises this is not helpful to our relationship."

- Independence and Self-Esteem

"I had been suffering from depression over the relapse in my condition, and not knowing what was happening to me physically led to me feeling quite suicidal at times, even to the point of trying to push myself from the hospital to the highway to push myself under a truck, and I was very angry at doctors who dismissed my pain and spasming as psychosomatic and not a medical condition at all and therefore they just dismissed me as psychosomatic."

IMPACT OF THE LEOP (CONT'D) ...

- At Work

"After leaving school I worked full-time for 34 years, but about 35 years after I had developed polio I was having a lot of trouble keeping on with my job.

For some years I had been having increasing pain and difficulty walking far or standing for long, until finally, after a process of elimination of other possible causes I was told that it was caused by Post Polio Syndrome.

During the day, as soon as I tire, I leave that occupation and do something else because I have found it is very bad to keep pushing myself."

IMPACT OF THE LEOP (CONT'D) ...

○ Financial Impact

- LEOP can lead to:
 - reduced financial independence including inability to pay for essential health services
 - need for earlier Government income support
- Due to polio, survivors often already have reduced education and employment opportunities
- LEOP negatively impacts on health, wellbeing, physical fitness with flow-on negative consequences on employment
- Polio survivors may need to:
 - modify work conditions
 - shorten work hours
 - retire early
 - change job tasks or employment
 - purchase aids and equipment, modify house, vehicle
 - use taxis instead of public transport

RESOURCES IN MANAGEMENT ...

- Neurology Consultant
- Rehabilitation Physician
- Physiotherapist
- Occupational Therapist
- Speech Pathologist
- Social Worker
- Respiratory Physician
- Orthotist
- Psychologist
- Polio Support Groups/Networks
- Affordable aids and equipment
- Home/vehicle modification



POLIO SUPPORT GROUPS ...

- 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



POLIO AUSTRALIA INCORPORATED
Representing polio survivors throughout Australia

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



Graeme Johnston, Fran Henke, Nola Stewart
Mornington Peninsula Post Polio Support Group



POLIO AUSTRALIA INCORPORATED
Representing polio survivors throughout Australia

STATE AND TERRITORY POLIO NETWORKS ...

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



POLIO AUSTRALIA INCORPORATED
Representing polio survivors throughout Australia

PEER SUPPORT IN THE STATES AND TERRITORIES ...

○ **New South Wales**

- **Polio NSW Inc:** 3 part-time staff / 25 support groups / membership and ad hoc philanthropic funding / established 1989

○ **Victoria**

- **Polio Network Victoria** (*a service of Independence Australia*): 1 part-time staff / 15 support groups / state Department of Human Services funds IA for 'information services' / established 1989
- **Post Polio Victoria Inc:** volunteer run advocacy service / ad hoc philanthropic funding / established 2011

PEER SUPPORT IN THE STATES AND TERRITORIES (CONT'D) ...

○ **Tasmania**

- **Post Polio Network - Tasmania Inc:** volunteer run service / 3 support groups / membership and ad hoc philanthropic funding / established 1998

○ **South Australia**

- **Polio SA Inc:** volunteer run service / 3 support groups / membership and occasional bequest funding / Disability Information and Resource Centre auspice \$50,000 grant from state Department of Community and Social Inclusion, which is used for service vouchers / established 1989

PEER SUPPORT IN THE STATES AND TERRITORIES (CONT'D) ...

o **Western Australia**

- **Post Polio Network of WA Inc:** 1 paid staff (CEO/RN) and volunteer run service / free in-house clinic in metro area / 3 support groups / funded through member donations and fund raising / established 1989

o **Queensland**

- **Spinal Injuries Association Qld:** 4 staff servicing total of 18 support groups - 6 are polio / combined grants from state Departments of Health & Disability fund 1 full-time Support Groups Co-ordinator and 1 part-time (30 hrs) admin support / SIA started supporting polio groups in 1994

PEER SUPPORT IN THE STATES AND TERRITORIES (CONT'D) ...

○ **ACT**

- Volunteer run support group only / part of Polio NSW

○ **NT**

- No support groups / polio survivors members of interstate Networks

DESIGNING A FUTURE ...

- May 2007 State Networks held national self-funded 'Designing a Future' conference
- Resolved to establish a national organisation *Polio Australia* (inc 2008)
- Objectives of Polio Australia:
 - articulation of the needs of polio survivors in Australia
 - centralised and consistent information provision
 - development and delivery of comprehensive education and training programs to the polio community and their health professionals



State Polio Network Delegates



POLIO AUSTRALIA'S PURPOSE ...

Mission

Polio Australia is committed to standardising quality information and service provision across Australia for polio survivors.

Vision

All polio survivors in Australia have access to appropriate health care and the support required to maintain independence and make informed lifestyle choices.



POLIO AUSTRALIA INCORPORATED
Representing polio survivors throughout Australia

KEY PROGRAMS ...

○ LEOP Self-Management Residentials

- In April 2010 Polio Australia conducted Australia's first three day Polio Health and Wellness Retreat in New South Wales
- Each day focussed on a different aspect of health and wellness: Body, Mind and Spirit
- The purpose of the Health and Wellness Retreats is to provide a holistic approach to managing the Late Effects of Polio and finding life balance for polio survivors and their families
- This chronic condition self-management model was based on a 2009 Polio Retreat held in Warm Springs, Georgia, USA, which was attended by four Australian polio survivors and Polio Australia's National Program Manger, Mary-ann Liethof
- In April 2011, a second Retreat was held in Victoria, with a third scheduled for Queensland in April 2012



POLIO AUSTRALIA INCORPORATED
Representing polio survivors throughout Australia

KEY PROGRAMS (CONT'D) ...

o Australian Polio Register

- The Australian Polio Register was established by Polio Australia in October 2010 to gather information on the numbers of polio survivors living in Australia today, whether or not they contracted polio in this country
- The Register captures data such as the survivor's name, birth year, polio details, where polio contracted, state/territory now resident, whether hospitalised (*only some details published, with permission*)
- Note: 16% contracted polio outside Australia
- Note: 18% not hospitalised (and 6% don't know whether hospitalised) when polio contracted
- To make the Register reflective of the unmet need for polio services throughout Australia, every Australian polio survivor urged to join the Polio Register, but lack of resources to promote throughout community a big issue



POLIO AUSTRALIA INCORPORATED
Representing polio survivors throughout Australia

KEY PROGRAMS (CONT'D) . . .



o Clinical Advisory Group

- To help achieve its Goals, Polio Australia established a Clinical Advisory Group (CAG) comprising health care professionals who are experts in their field and have knowledge about polio and its late effects
- The group composition represents health care professionals from every state who specialise in diverse areas such as immunisation, rehabilitation, physiotherapy, orthotics, psychology, respiratory and research



POLIO AUSTRALIA INCORPORATED
Representing polio survivors throughout Australia

KEY PROGRAMS (CONT'D) . . .

○ Clinical Advisory Group

- Tasked with standardising quality information and service provision across Australia, incorporating appropriate diagnosis and management of LEOP, to ensure that polio survivors have access to appropriate health care and the support required to maintain independence and make informed lifestyle choices. HOWEVER, resources are needed to achieve this.
- 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.



WHERE TO FROM HERE ...

- Roundtable Forum 30 March 2012 takes evidence from a range of polio and post-polio experts
- Evidence, submissions and recommendations considered and Committee report released
- Late Effects of Polio recognised as a substantial and urgent national health concern with diagnosis, management and support readily available across Australia for the nation's polio survivors, both young and old

