

# People with Post Polio Syndrome – an ageing population



**Mornington Peninsula Post Polio Support Group**

# INTRODUCTION

- Presenters:
  - **Margaret Cooper**, 'consumer' and member of the Polio Networks' Polio Advisory Committee.
  - **Mary-ann Liethof**, Community Officer, Polio Network.
- Polio Network, a service of ParaQuad Victoria, is a unique example of a service provider and consumers working together to better the health and social participation of a specific community.

# CONSUMER PARTICIPATION

- This presentation highlights the role of the Polio Network's post polio support groups in meeting the needs of polio survivors by providing empathy, information and social participation.

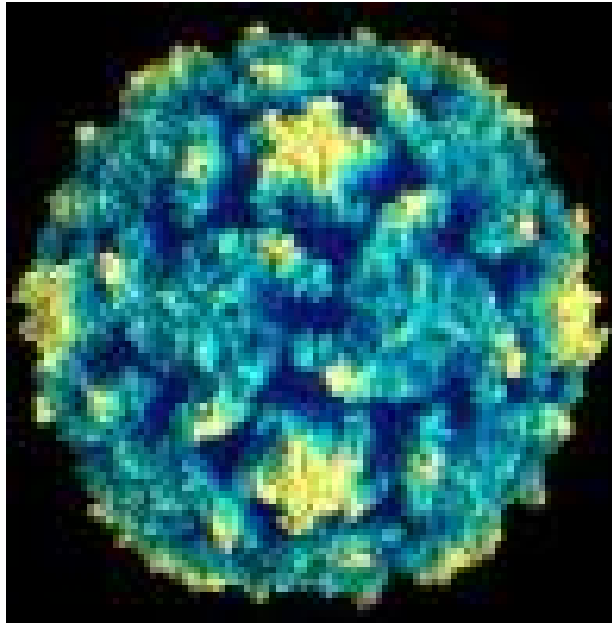


Geelong Hydrotherapy Post Polio Support Group

# SUCCESS FACTORS

- Polio survivors are intensely curious about any changes in their abilities and have taken the initiative to research their condition.
- Established post polio support groups which are now located in 20 communities throughout Victoria.
- Groups offer support, information and shared experiences in dealing with post polio syndrome.
- Polio Networks' CD model.

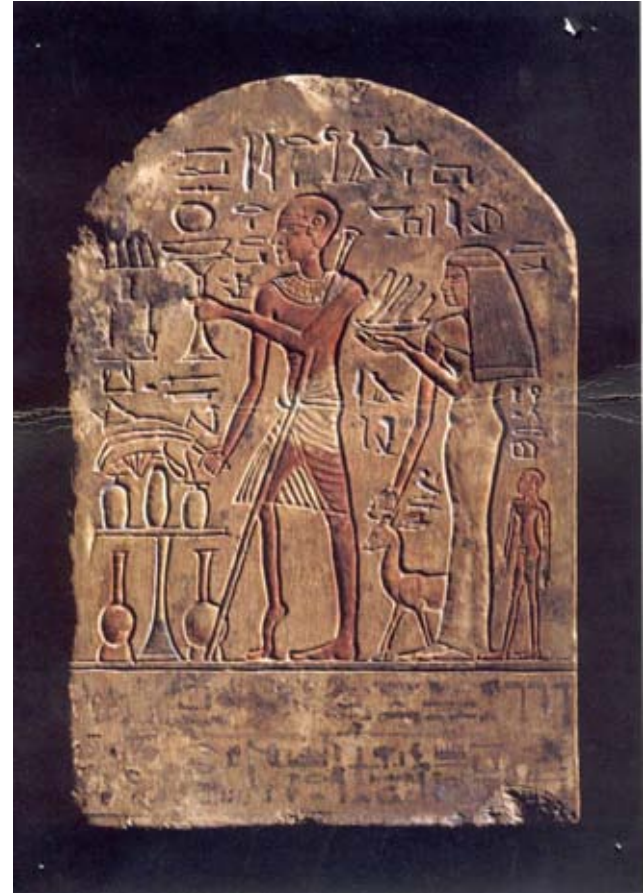
# UNDERSTANDING POLIOMYELITIS (POLIO)



The polio virus

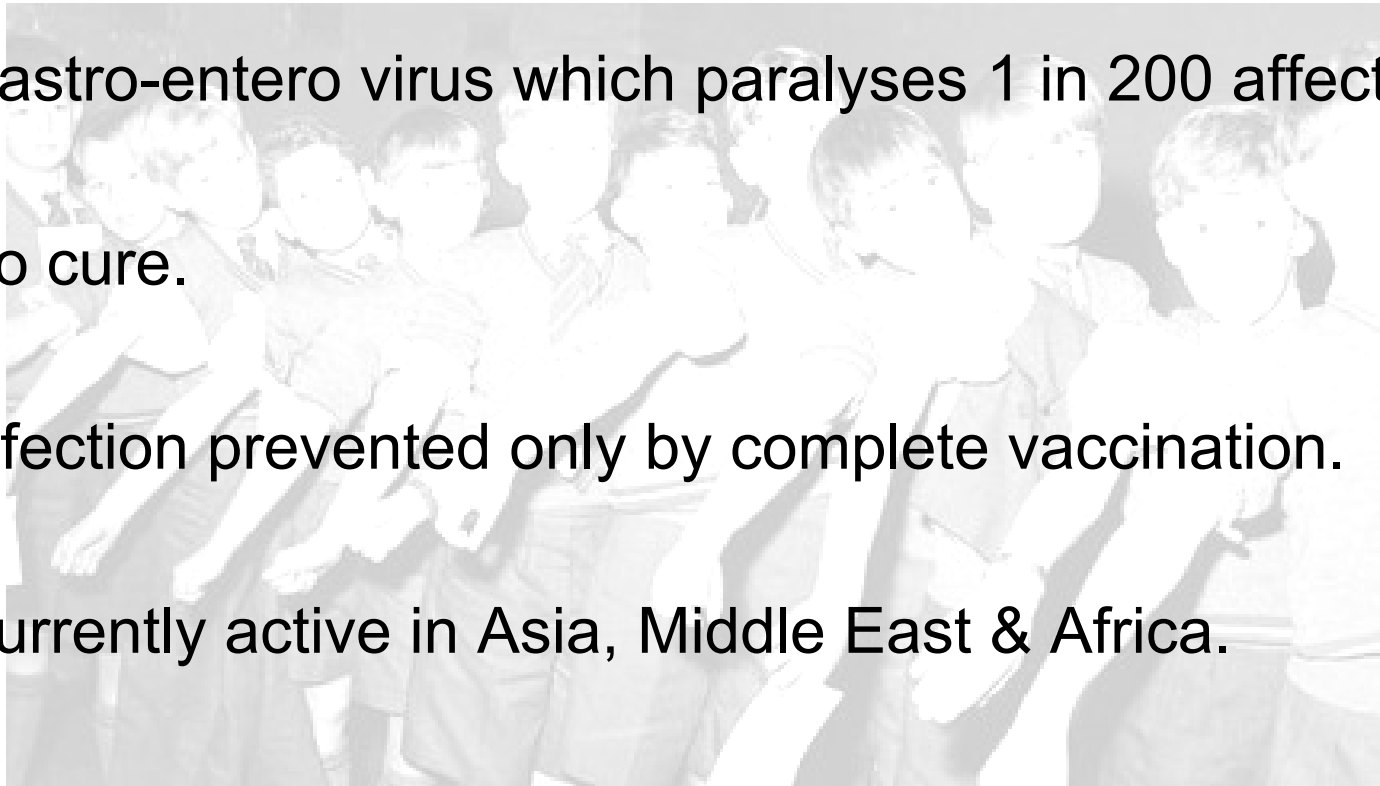
Circa  
1580 BC

Polio is  
an  
ancient  
disease



# Understanding polio (cont'd)

- Gastro-entero virus which paralyses 1 in 200 affected.
- No cure.
- Infection prevented only by complete vaccination.
- Currently active in Asia, Middle East & Africa.



# Understanding polio (cont'd)

- Causes permanent destruction of the nerve connection between the spinal cord and the muscle cell.
- Leads to uneven paralysis of muscles.
- Uneven muscle stresses on bones and joints.
- Results in bending of some bones e.g. the spine, with consequent joint damage.

# Understanding polio (cont')



# Understanding polio (cont')

- Polio epidemics ravaged Australia, particularly the East coast, all through the first half of the 1900's, paralyzing up to 70,000\* people between 1930 & 1960.
- The Salk (injected), then Sabin (oral) vaccines were made available in the late 1950's.
- In the last 3 decades, there have only been 12 cases of polio in Australia.

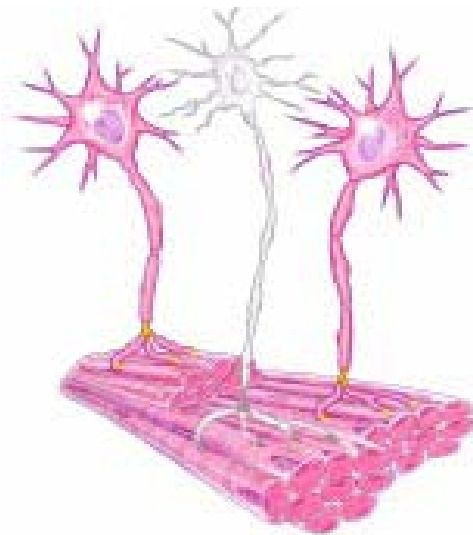
# POST POLIO SYNDROME

- During the 1970's & 80's polio survivors (now aged in their 30's and 40's) began to report symptoms which were new to them.
- These symptoms became known as post-polio syndrome or late effects of polio.
- Post-polio syndrome or the late effects of polio include:
  - New muscle weakness
  - Joint and/or muscle pain
  - Muscle atrophy
  - Unusual and incapacitating fatigue
  - Breathing/speech problems
- These symptoms were verified by UK and USA researchers.

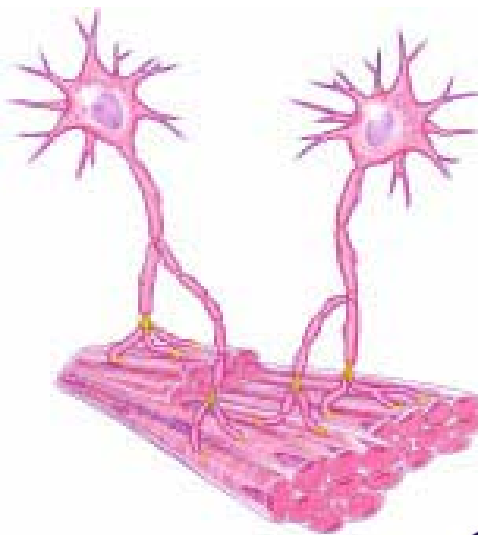
Anderson, Levine, & Gellert 1972, Campbell, Williams, & Pearce 1969, Mulder, Rosenbaum, & Laton 1972, Howard, Wiles, and Spencer 1988, Cashman, Siegel, and Antel 1987, Bruno 2002, Perry 2004, Klingbeil 2004

# Post Polio Syndrome (cont'd)

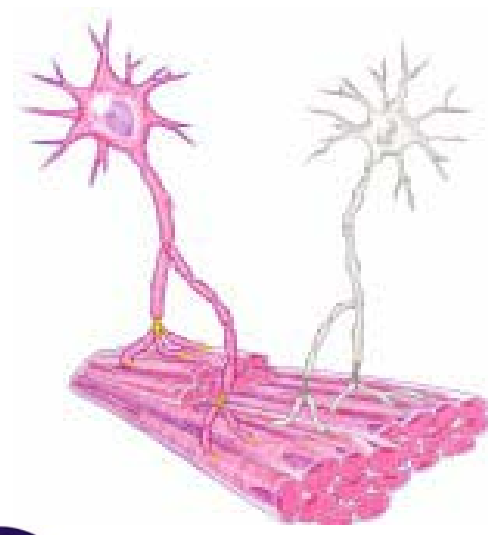
**Acute polio:** some neurons die, while others survive



**Stable post-polio period:** the surviving neurons cover more territory than they did before the polio by sprouting collateral fibres



**Post-polio syndrome:** more neurons are lost by normal attrition, leading to muscle weakness



# THE POLIO COMMUNITY

- an ageing population



# The polio community (cont'd)

- Polio survivors are fearful of any threat to independence. Why?
  - Australians growing up in '30's, '40's, 50's, 60's & 70's experienced very little community support for people who were 'different'.
  - Pursued 'normal' life goals zealously.



# The polio community (cont'd)

- Often described as 'Type A' personalities, i.e. extremely independent and like to be in control.
- Majority left rehabilitation centres and did not need to be in contact with disability service providers.
- Alternative to coping was poverty and geriatric nursing homes.
- Ageing polio survivors who develop post polio syndrome are very concerned about the repercussions on their families.

# SIGNIFICANT LEARNINGS

- Americans were first to explore the late effects of polio in the late 1960's and early 1970's.
- The editor of the 'Rehabilitation Gazette', dedicated a whole edition to ageing issues (Laurie 1980).
- The response by polio survivors led her to organize the first *Ageing with Polio Conference* (Laurie 1981).
- People attending the American conferences brought back information to Australia/Victoria.

# STRATEGIES TO ADDRESS BARRIERS TO PARTICIPATION



# Strategies to address barriers (cont'd)

- In response to the American findings, in 1987, polio survivor Edith Hall, then CEO of ParaQuad Vic, committed resources to develop a network of support groups.
- ParaQuad subsequently secured DHS funding and employed a Community Officer to co-ordinate the Polio Network, guided by an elected Polio Advisory Committee.
- The Polio Network is a free service with more than 1600 'members' on the database.
- Information is regularly exchanged between support groups, individual members, and the Polio Network via community information sessions, website, newsletters, email, and Polio Day.

# Strategies to address barriers (cont'd)

- There are now 20 support groups in Victoria, 19 of which are facilitated by volunteers who have had polio.
- Support group contacts provide information to fellow polio survivors, and any other interested people, about post polio syndrome and local resources.
- Support group meetings offer people unused to discussing personal struggles a place to feel free to talk about difficulties in managing their new disabilities.
- Support groups also provide important social support.

# CHALLENGES REMAINING

- With the closure of polio treatment facilities such as Fairfield Hospital, there has been no longitudinal, or for that matter any, health care research which might have assisted polio survivors move gently into ageing.
- People with post polio symptoms are looking for expert advice on management strategies to maximise independence and mobility.
- Most doctors and healthcare workers have no experience with polio, including aged care teams.
- Former expert clinicians have retired or died.
- In 1998 polio survivors were given access to a new clinic funded by DHS – Polio Services Victoria.
- Demands on this service have since increased fourfold.

# Challenges remaining (cont'd)

- Tens of thousands of Australians live with the legacy of polio, yet it is a little known fact that people who have previously had polio can experience a return of the symptoms 40 years or more after their initial recovery.
- The symptoms of post polio syndrome are often associated with the ageing process experienced by the general population, making the diagnosis of post polio syndrome difficult.
- People experiencing post polio syndrome often feel frustrated and isolated as they try to come to terms with the deterioration in their physical abilities, and as they try to find health professionals who have an understanding of the condition.

# CONCLUSION

Polio may be gone . . .



but its impact on lives continues!