

# 1<sup>st</sup> Australasia-Pacific Post-Polio Conference

## *Polio – Life Stage Matters*

*Sydney, Australia*

*20–22 September 2016*



### *Program and Abstracts*

#### CONFERENCE STEERING COMMITTEE

Dr Stephen de Graaff, Rehabilitation Physician and Conference Chair  
Epworth Health (Victoria, Australia), [Steve.Degraaff@epworth.org.au](mailto:Steve.Degraaff@epworth.org.au)

Joan Headley, Executive Director  
Post-Polio Health International (St Louis, USA), [director@post-polio.org](mailto:director@post-polio.org)

Mary-ann Liethof, National Program Manager  
Polio Australia (Victoria, Australia), [mary-ann@polioaustralia.org.au](mailto:mary-ann@polioaustralia.org.au)

John McFarlane, President  
European Polio Union (Ireland), [europeanpolio@eircom.net](mailto:europeanpolio@eircom.net)

Dr Margaret Peel, PhD  
Polio Australia Board Member (Queensland, Australia)

Jill Pickering, OT (Ret)  
Polio Australia Volunteer (Victoria, Australia), [jill@polioaustralia.org.au](mailto:jill@polioaustralia.org.au)

Dr Michael Summers, PhD, Evaluator/Senior Policy Advisor  
(Victoria, Australia)

Liz Telford, Post Polio Victoria Secretary  
(Victoria, Australia), [postpolio victoria@gmail.com](mailto:postpolio victoria@gmail.com)

Gillian Thomas, President, Polio NSW, and Vice-President, Polio Australia  
(New South Wales, Australia), [gillian@polioaustralia.org.au](mailto:gillian@polioaustralia.org.au)

Dr John Tierney, OAM PhD, President and National Patron, Polio Australia  
(New South Wales, Australia), [john@polioaustralia.org.au](mailto:john@polioaustralia.org.au)

#### SCIENTIFIC COMMITTEE

Sarah Anderson, Prosthetist and Orthotist and Lecturer  
La Trobe University (Victoria, Australia), [sarah.anderson@latrobe.edu.au](mailto:sarah.anderson@latrobe.edu.au)

Merete Bertelsen, Physiotherapist  
Special Hospital for Polio and Accident Patients (Copenhagen, Denmark),  
[mbe@specialhospitalet.dk](mailto:mbe@specialhospitalet.dk)

Dr Stephen de Graaff, Rehabilitation Physician  
Epworth Health (Victoria, Australia), [Steve.Degraaff@epworth.org.au](mailto:Steve.Degraaff@epworth.org.au)

Joan Headley, Executive Director  
Post-Polio Health International (St Louis, USA), [director@post-polio.org](mailto:director@post-polio.org)

Dr Ian Neering, PhD  
Researcher (Australian Capital Territory, Australia)

Dr Peter Nolan, General Physician  
St Andrews Hospital Toowoomba (Queensland, Australia), [reception@bowtiemedical.com.au](mailto:reception@bowtiemedical.com.au)

Dr Mary Westbrook, PhD, Psychologist (Ret)  
(New South Wales, Australia)

Dr Michael Summers, PhD, Evaluator/Senior Policy Advisor  
(Victoria, Australia)

#### TABLE OF CONTENTS

Programme	732
Plenary lectures (PL01–PL04)	735
Keynote lectures (KL01–KL20)	736
Symposium lectures (SL01–SL29)	741
Free papers (FP01–FP14)	748
Polio stories (PS01–PS05)	752
Poster presentations (PP01–PP08)	754
Author index	756

#### SPONSORS:



POST-POLIO HEALTH INTERNATIONAL  
INCLUDING INTERNATIONAL VENTILATOR USERS NETWORK



**ResMed**  
Changing lives  
with every breath

## Greetings from the Chair

*This special issue of the Journal of Rehabilitation Medicine contains all the abstracts of the 1<sup>st</sup> Australasia-Pacific Post-Polio Conference: Polio - Life Stage Matters, held from 20-22 September 2016 in Sydney, Australia.*

*The Conference title reflects on the challenges faced by the survivors of the initial poliomyelitis infection throughout their lives, with an emphasis on critical management strategies and timelines. Decline in function associated with weakness, fatigue and pain can have a profound impact on the polio survivor's wellbeing and health. Age, geographic situation, community and financial resources, medical knowledge and practices as well as recognition of the Post-Polio Syndrome all influence how the polio survivor is managed and assisted.*

*The diversity of the presentations reinforces the fact that throughout the world addressing the challenges for the polio survivor vary enormously and the opportunity to come together in Sydney provides an environment for promotion of evidence-based practice to improve the health and wellbeing of all polio survivors internationally. Contemporary and innovative concepts are explored and expanded upon ensuring debate and discussion.*

*The 1<sup>st</sup> Australasian-Pacific Post-Polio Conference has attracted international and local presenters with a wealth of experience in the management, treatment and rehabilitation of polio survivors. These health care workers and researchers provide a fertile program content of current practice and literature to enhance the management and research into the care of the polio survivor now and in the future.*

*Dr Stephen de Graaff MBBS FAFRM (RACP)*

*Conference Chair, 1<sup>st</sup> Australasia-Pacific Post-Polio Conference*

## PROGRAMME

### **Tuesday 20<sup>th</sup> September 2016**

#### 09.30–10.00: Plenary lecture (PL01)

**What polio causes, does not cause and might cause**  
Marny Eulberg, Retired Medical Doctor 735

#### 10.00–11.00: Keynote Lectures (KL01–KL02)

**The challenges of managing pain in the polio survivor**  
Stephen de Graaff, Rehabilitation Physician, Director of Pain Services 736

**Orthotic needs for younger polio survivors**  
Darren Pereira, Principal Orthotist & Director 736

#### 10.00–11.00: Symposium Presentations (SL01–SL03)

**The lived experiences of older people with post-polio syndrome in Australia**  
Pat Dorsett, Social Worker, with Sandra Woodbridge, Human Services Professional 741

**Long-term socio-economic consequences and health care cost of poliomyelitis**  
Nete Munk Nielsen, Researcher 741

**Long-term mortality and morbidity following poliomyelitis. A register case control study of a cohort of Danish poliomyelitis patients**  
Lise Kay, Urologist 741

#### 11.00–11.30: Morning tea and Poster viewing

#### 11.30–12.30: Keynote Lectures (KL03–KL04)

**Physiotherapy for post-polio patients as part of an interdisciplinary rehabilitation program**  
Merete Bertelsen, Physiotherapist 736

**Attendee feedback review of Mt Wilga LEoP clinic**  
Helen Mackie, Rehabilitation Physician 736

#### 11.30–12.30: Symposium Presentations (SL04–SL06)

**Polio Services Victoria model of care**  
Yan Chow, Rehabilitation Physician 741

**A hydrotherapy transition model for polio survivors**  
Russel Anbiah, Physiotherapist (presented by Yan Chow) 742

**Fatigue self-management course**  
Margaret Petkoff, Occupational Therapist 742

#### 12.30–13.30: Lunch and Poster viewing

#### 13.30–15.30: Keynote Lectures (KL05–KL08)

**Continence issues for post-polio patients**  
Lise Kay, Urologist 736

**Ventilation advancements for polio patients over the decades**  
Anne Duncan, Clinical Nurse Consultant 737

**Telemedicine opportunities: potential health service provision and educational options for remote and/or difficult to reach post-polio patients of all ages**  
William DeMayo, Rehabilitation Physician 737

**Four decades of working with post-polio patients**  
Ann Buchan, Neurophysiotherapist 737

13.30–15.30: Symposium Presentations (SL07–SL11)

**Quality of life and fatigue severity scores of attendees of the Mt Wilga LEOp assessment clinic**  
*Catriona Morehouse, Physiotherapist* 742

**How new bracing methods help strengthen muscles, while reducing fatigue, and falls**  
*Marmaduke Loke, Prosthetist and Orthotist* 742

**Best practice in providing assistive technology and environmental adaptations to the polio community**  
*Natasha Layton, Occupational Therapist* 743

**Establishing consensus of exercise options for post-polio**  
*Tim Lathlean, Accredited Exercise Physiologist* 743

**Survey of health professionals with experience in post-polio patient care**  
*Joan Headley, Executive Director* 743

13.30–15.30: Free papers (FP01–FP05)

**The benefits and dangers of social media in the care, treatment and management of post-polio syndrome – an observational study**  
*John R. McFarlane, President, European Polio Union*  
*(presented by Gillian Thomas)* 748

**Universal design: beyond the access codes**  
*Jane Bringolf, Community Services* 748

**LEOp: clinical practice workshop series for allied health professionals**  
*Mary-ann Liethof, National Program Manager, Polio Australia* 748

**A perfect storm? Salk vaccine shortages and the polio epidemics in Australia**  
*Kerry Highley, Medical Historian* 748

**Brace yourself: The polio experience as visual language from a daughter's/carer's perspective**  
*Danica Knezevic, Artist* 749

15.30–16.00: Afternoon tea and Poster viewing

16.00–17.00: Keynote Lectures (KL09–KL10)  
**Solution based treatment offers positive life changes & new hope for polio survivors**  
*Marmaduke Loke, Prosthetist and Orthotist* 738

**Developing a late effects clinic – WA experience**  
*Gnanaletchumy Jegasothy, Retired Physiotherapist* 738

16.00–17.00: Symposium Presentations (SL12–SL14)

**The profile of people with polio/post-polio accessing the Enable NSW assistive technology program**  
*Anna Hartley, Orthotist; with Christa Roessler, Prosthetist & Occupational Therapist* 743

**Aerobic exercise training in post-polio syndrome: a process evaluation**  
*Eric Voorn, Researcher* 743

**Every bite counts – why food matters**  
*Melinda Overall, Nutritionist & Lecturer in Nutritional Medicine* 744

16.00–17.00: Free papers (FP06–FP08)

**Finding me: being Aboriginal and ill in Australian society in the 1950s and 60s**  
*Gayle Kennedy, Author* 749

**Quality patient care – the polio survivor's perspective**  
*Liz Telford, Social Worker & Polio Health Advocate* 749

**But how many of you are there?**  
*Gillian Thomas, Vice-President, Polio Australia* 749

17.30–19.30: Cocktail Party**Wednesday 21<sup>st</sup> September 2016**09.30–10.00: Plenary lecture (PL02)

**Evaluation and improvement of functional abilities for post-polio patients**  
*Frans Nollet, Professor in Rehabilitation Medicine* 735

10.00–11.00: Keynote Lectures (KL11–KL12)

**Advances in the surveillance, control and elimination of polio**  
*Robert Booy, Head of Clinical Research* 738

**IvIg as a treatment for post-polio syndrome: trial results**  
*TBA* 738

10.00–11.00: Symposium Presentations (SL15–SL17)

**Medication and the post-polio patient**  
*Lise Kay, Urologist* 744

**Falls prevention**  
*Merete Bertelsen, Physiotherapist* 744

**Polio effects may just be the tip of the iceberg**  
*Marny Eulberg, Retired Medical Doctor* 744

10.00–11.00: Free papers (FP09–FP11)

**Ageing successfully with a long-term disability: insights from Australian polio survivors**  
*Nicola Heath, PhD Candidate* 750

**The 'golden hour' for risk screening and intervening to prevent pressure ulcers post-polio**  
*Catherine Sharp, Expert Witness Nurse Consultant* 750

**Progress towards establishing post-polio clinics in New Zealand**  
*Julie Rope, Physiotherapist, with Gordon Jackman, Program Manager* 750

11.00–11.30: Morning tea and Poster viewing11.30–12.30: Keynote Lectures (KL13–KL14)

**Cough, spit and breathlessness in polio survivors**  
*Peter Nolan, General Physician* 738

**Management of spinal issues in polio patients**  
*Carol Vandenaeker-Albanese, Physical Medicine & Rehabilitation* 738

11.30–12.30: Symposium Presentations (SL18–SL20)

**Swollen polio legs**  
*Helen Mackie, Rehabilitation Physician* 744

**Pre-habilitation: preparing for surgery**  
*Stephen de Graaff, Rehabilitation Physician, Director of Pain Services* 744

<b>Rehabilitation following hip arthroplasty in patients with residual poliomyelitis</b> <i>Nigel Quadros, Rehabilitation Physician</i>	745	<i>16.00–17.00: Symposium Presentations (SL27–SL29)</i>
<i>11.30–12.30: Free papers (FP12–FP14)</i>		<b>Post-polio syndrome: unanswered questions</b> <i>Frans Nollet, Professor in Rehabilitation Medicine</i>
<b>Producing the UK PPS management guide for health care professionals</b> <i>Frances Quinn, British Polio Fellowship Expert Panel Member</i>	751	<b>The differing needs of younger polio survivors</b> <i>TBA</i>
<b>How the power of one achieves inclusive communities</b> <i>John Mayo, Chief Advisor</i>	751	<b>Sophisticated bracing solutions offer improved life changes</b> <i>Bruce (Mac) McClellan, Prosthetist and Orthotist</i>
<b>“Closing the circle” developing a partnership between polio survivors and Rotary – the Australian experience</b> <i>John Tierney, President and National Patron, Polio Australia</i>	751	<i>19.00: Gala Dinner</i>
<i>12.30–13.30: Lunch and Poster viewing</i>		<b>Thursday 22<sup>nd</sup> September 2016</b>
<i>13.30–15.30: Keynote Lectures (KL15–KL18)</i>		<i>09.30–10.00: Plenary lecture (PL03)</i>
<b>Demystifying treatment of the polio body</b> <i>Melissa McConaghy, Physiotherapist &amp; Practice Principal</i>	739	<b>Future proofing post-polio services</b> <i>Mary-ann Liethof, Joan Headley and Gordon Jackman</i>
<b>Case consultation: psychotherapy with a polio survivor</b> <i>Stephanie Machell, Psychologist</i>	739	<i>10.00–14.30: Mainstream (PS01–PS05)</i>
<b>The legendary walker and unwitting biomechanist</b> <i>Bernard Badorrek, Prosthetist and Orthotist</i>	739	<b>10.00–10.30: Polio eradication update</b> <i>Jenny Horton, Rotarian</i>
<b>Impact of osteoporosis and its management in survivors of poliomyelitis</b> <i>Nigel Quadros, Rehabilitation Physician</i>	739	10.30–11.00: Morning Tea and Poster Viewing
<i>13.30–15.30: Symposium Presentations (SL21–SL26)</i>		<b>11.00–12.30: Polio Stories</b>
<b>Sleep hygiene - sleep as a trained behaviour. How to improve duration and quality of sleep to improve health and wellness</b> <i>William DeMayo, Rehabilitation Physician</i>	745	- <b>Kenya, Mau-Mau and polio in 1954</b> <i>Catherine Sharp, Expert Witness Nurse Consultant</i>
<b>Anaesthesia for the post-polio patient</b> <i>Christine Ball, Anaesthetist</i>	745	- <b>Polio management in life stages</b> <i>Sai Padma Bellana, Advocate and Social Activist; with Pragyanand Busi, Therapist</i>
<b>Finding the right mask</b> <i>Anne Duncan, Clinical Nurse Consultant</i>	745	- <b>Japanese Network of polio survivors - history, activities and future visions</b> <i>Tae Shibata, Welfare Advisor</i>
<b>Posture and musculoskeletal pain</b> <i>Carol Vandenakker-Albanese, Physical Medicine &amp; Rehabilitation</i>	746	- <b>Living with polio in three continents</b> <i>Neena Bhandari, Foreign Correspondent</i>
<b>Serum carnitine levels: a useful indicator to determine effectiveness of L-carnitine supplementation as a clinical treatment for post-polio fatigue</b> <i>Tessa Jupp, Registered Nurse</i>	746	12.30–13.30: Lunch and Poster Viewing
<b>Polio and PPS: Changing Identities</b> <i>Stephanie Machell, Psychologist</i>	746	<b>13.30–14.30: Post-Polio Service Dreaming</b> 14.30–15.00: Afternoon Tea and Poster Viewing
<i>15.30–16.00: Afternoon tea and Poster viewing</i>		<b>15.00–16.30: Post-Polio Programs: Where to from here?</b>
<i>16.00–17.00: Keynote Lectures (KL19–KL20)</i>		<i>10.00–16.30: Master Classes for Health Professionals</i>
<b>Long-term poliovirus infection and its possible impact on post-polio syndrome</b> <i>Antonio Toniolo, Professor of Medical Microbiology and Virology</i>	740	<b>10.00–12.00: Two-Hour Master Classes</b>
<b>Post-polio research: why and what?</b> <i>Joan Headley, Executive Director</i>	740	- <b>Models for setting up a polio clinic and telemedicine for remote patients</b>
		- <b>Diagnosing PPS vs LEOp</b>
		- <b>Gait assessments and orthotics</b>
		12.00–13.00: Lunch and Poster Viewing
		<b>13.00–15.00: Two-Hour Master Classes</b>
		- <b>Physiotherapy assessments and exercise prescription</b>
		- <b>Comorbidities: what is polio and what is not? Pharmaceutical intervention and contraindications</b>
		- <b>Respiratory and sleep issues and management</b>
		<b>15.00–16.30: 90-Minute Master Classes</b>
		- <b>Psychological factors</b>
		- <b>Promising research and clinical trials</b>
		<i>16.30–17.00: Plenary lecture (PL04)</i>
		<b>Closing plenary: dancing in my dreams</b> <i>Kerry Highley, Medical Researcher &amp; Author</i>



**PLENARY LECTURES (PL01-PL04)****PL01****WHAT POLIO CAUSES, DOES NOT CAUSE AND MIGHT CAUSE**

**Marny Eulberg, Retired Medical Doctor**  
USA

Sometimes polio survivors and even their physicians assume all medical conditions that develop years after the initial acute polio are directly related to the prior polio OR that none of their new symptoms/conditions are related to the polio. Dr. Eulberg and the Medical Advisory committee of Post-Polio Health have developed this general classification of symptoms/diseases and defined whether there is a direct causal relationship to the prior polio infection, a possible causal connection or no connection.

**PL02****EVALUATION AND IMPROVEMENT OF FUNCTIONAL ABILITIES FOR POST-POLIO PATIENTS**

**Frans Nollet, Professor in Rehabilitation Medicine**  
Academical Medical Hospital, The Netherlands

The clinical challenge is to maintain functioning and quality of life of aging individuals who contracted polio in their early childhood. Due to decline of muscle function caused by post-polio syndrome (PPS), often in combination with comorbidity, aging effects, and secondary degenerative conditions of the locomotory system, disability increases over time. Although the rate of decline in muscle function is slow, the progression over years is considerable, and may cause overuse symptoms, such as joint and muscle pains and severe fatigue. Before the diagnosis of PPS can be made, other medical conditions that may explain symptoms must have been ruled out. A thorough, individual medical and functional evaluation is required because each individual is different with respect to severity and extent of residual involvement by polio and growth deviations. In the assessment of symptoms and functional limitations, a biomechanical analysis of movement, taking into account the distribution of muscle weakness and deformities, can help to understand overuse complaints. Regarding functioning in daily life, attention should be given to the individual's activity pattern, physical effort, environment and personal characteristics. Rehabilitation treatment is multidisciplinary and tailored to the needs of the individual patient. The aim is to rebalance between physical capacity and physical demands in daily life. Physical therapy aims to reduce symptoms of overuse of weakened muscles, to limit the disuse of non-affected muscles, and to improve cardiorespiratory condition. Although an active life style is to be advised, physical overload in daily life must be avoided. This often requires changes in activity pattern and may imply the use of orthotics, mobility assistive devices and home adaptations. For polio survivors, behaviour modification and the acceptance of devices and help is usually difficult and often requires psychological support. Since rehabilitation interventions lack high quality evidence, randomised controlled trials of rehabilitation interventions, including the evaluation of cost-effectiveness, are needed to substantiate multidisciplinary symptomatic treatment.

**PL03****FUTURE PROOFING POST-POLIO SERVICES**

**Mary-ann Liethof, Joan Headley and Gordon Jackman**  
Polio Australia, Post-Polio Health International (USA), and Polio New Zealand

What are three of the world's key post-polio organisations doing to 'Future Proof' services to polio survivors, both now and into the future? This joint presentation will showcase the programs and strategies we are currently doing, or planning to undertake, to ensure our post-polio communities are able to access the services they need as they age. Also, what legacy will we be leaving when, in 20 or so years from now, the majority of the Western world's polio survivors no longer require specific post-polio services? The research, publications, various resources, web content, numbers of health professionals educated, support groups established, and program funding support for developing countries, should continue to inform post-polio services for younger polio survivors in developing countries.

**PL04****CLOSING PLENARY: DANCING IN MY DREAMS**

**Kerry Highley, Medical Researcher & Author**  
*Dancing in My Dreams: Confronting the Spectre of Polio, Australia*

Across most of the world, an entire generation has lived free from the spectre of polio, but for fifty years during the twentieth century that fear was overwhelming. Polio became every parent's worst nightmare, and panic drove rational people to do bizarre things to protect their children. Survivors of the disease often found that they faced a world unfriendly to their disability. How to treat polio survivors generated a rift between the medical community and its recommendations and the approaches of those advocating alternative therapies for the paralysed body. In pre-Second World War Australia, two women symbolised this split. In her clinics in Australia, England, North America and Canada, Sister Elizabeth Kenny championed and practised a treatment diametrically opposed to the widely used 'orthodox' approach of Victorian Dr Jean Macnamara. In Australia, the public's reverence of the medical profession entrenched her approach until well after most Western countries had abandoned it. *Dancing in My Dreams* details the disease of polio and its treatment, the scientific endeavour that led to the discovery of the poliovirus, and the studies in virology and immunology that culminated in the production of a polio vaccine. It highlights the experiences of patients and the voices of survivors, revealing how ethnicity, class, age and gender all mediated an individual's reaction to having polio, which included fear, rejection, denial and anger.

## KEYNOTE LECTURES (KL01-KL20)

## KL01

**THE CHALLENGES OF MANAGING PAIN IN THE POLIO SURVIVOR****Stephen de Graaff, Rehabilitation Physician, Director of Pain Services***Epworth Health, Australia*

Persistent pain affects approximately 1 in 5 Australians and its prevalence increases with age. It is associated with substantial disability, mood and behavioural changes, adverse psychosocial circumstances, financial, employment and legal difficulties and frequent use of health services and overuse of over the counter analgesics. It is important where possible to define the cause of one's pain. This allows for appropriately targeted treatment. In the polio survivor's situation, a clear understanding of the sequelae of polio is necessary to ensure all preventative and interventional treatments are appropriate. The development of the multi-disciplinary persistent pain management approach targets the pain sufferer's ability to understand their pain, improve their physical function, modify their perceived level of pain and suffering and develop coping strategies to promote self-management. This presentation will discuss the background to persistent pain and the processes and structures necessary for successful pain management in the polio survivor.

## KL02

**ORTHOTIC NEEDS FOR YOUNGER POLIO SURVIVORS****Darren Pereira, Principal Orthotist & Director***NeuroMuscular Orthotics, Australia*

Our close geographical proximity to South East Asia and the Sub-Continent, in conjunction with migration to Australia from the African continent, has meant that there is a large number of younger clients with polio who require orthotic management. NeuroMuscular Orthotics specialises in the complex orthotic management of neurological disorders. We currently consult with over 100 polio clients who are under the age of 40 and just having the ability to walk is no longer enough to satisfy their needs. This presentation will focus on some of the orthotic solutions that we have developed with the younger client to allow them to fully participate in all aspects of their life and will address the following: – Accommodating a lower limb orthosis into a street, dress or trendy shoe. – Accommodating a large length discrepancy without adding all of it externally to a shoe. – Accommodating shoes with varying heel height without re-making the lower limb orthosis. – Designing a waterproof orthosis for water based activities. – Developing a recreational orthosis for a sport specific role

## KL03

**PHYSIOTHERAPY FOR POST-POLIO PATIENTS AS PART OF AN INTERDISCIPLINARY REHABILITATION PROGRAM****Merete Bertelsen, Physiotherapist***Specialized Hospital for Polio and Accident Victims, Denmark*

Rehabilitation of a polio survivor will in many cases need an interdisciplinary team comprising all or some of the mentioned professionals: Medical doctor, occupational and physical therapist, psychologist, orthopedic technician, social worker and dietician. Physiotherapy is often an important part of the team work as many polio survivors suffer from reduction in physical functioning, fatigue and pain. Most polio survivors in western countries are elderly and post-polio problems are often combined with other health issues which should be taken into account. As a result of immigration from developing countries we also see younger polio survivors who have different issues to deal with such as pregnancy, handling small children, vo-

litional problems and other physical problems such as contractures and leg length discrepancies. In both patient groups it is of great value that the interdisciplinary team work closely together and include the patient as a part of the team. The team must set short and long term goals for the rehabilitation, make a rehabilitation plan and evaluate the results. Physiotherapy will typically comprise pain reduction, recommendation on technical aids and bandages, physical exercise, patient education/empowerment and energy management. This presentation will include how we organize the interdisciplinary team work and the typical physiotherapy assessment and intervention at the Specialized Hospital for Polio and Accident Victims in Denmark.

## KL04

**ATTENDEE FEEDBACK REVIEW OF MT WILGA LEOP CLINIC****Helen Mackie, Rehabilitation Physician***Mt Wilga Private Rehabilitation Hospital, Australia*

There are around 400,000 polio survivors living in Australia, one third who are likely to be in NSW. Polio survivors are at risk of developing late effects of polio (LEoP) including post-polio syndrome, weakness, fatigue, pain, musculoskeletal problems, breathing and sleeping problems. The need for a specialist polio assessment clinic was identified by Polio NSW. *Introduction:* In response to the identified need, a LEoP assessment clinic was commenced at Mt Wilga Private Hospital (MWPH) in April 2015. The Clinic undertakes assessments by a Rehabilitation Physician, Physiotherapist and Occupational Therapist to identify the attendees' current and possible future issues and to provide to the attendees and their referring GPs information and options for further investigation, therapy and services, including the multi-disciplinary rehabilitation program on-site. *Aim:* To evaluate the MWPH LEoP Clinic, using attendee feedback survey responses. *Results:* The presentation will discuss the establishment of a LEoP assessment Clinic at MWPH and the outcome of that clinic's assessment for those attending. Data will be presented including demographic and baseline data, service uptake following and outcomes. How this data has informed the development of the clinic will be discussed including lessons learned and challenges involved in setting up a new service for Polio survivors. *Implications for practice:* Results will highlight the needs of polio survivors. Results will inform the ongoing improvement of the MWPH LEoP clinic as well as act as a resource for Clinics which may develop on other sites.

## KL05

**CONTINENCE ISSUES FOR POST-POLIO PATIENTS****Lise Kay, Urologist***Specialized Hospital for Polio and Accident Victims, Denmark*

Although the primary characteristics of an acute polio infection are flaccid pareses, a review of reports from the polio epidemics also reveals that about 20% of the patients also experienced bladder symptoms mostly as retention, but also as incontinence. It is also noted that these problems generally solve themselves, as the acute polio resolves. Later in life polio patients once again experience voiding problems twice as often as the background population, mainly as urgency and urge incontinence. Neurological control of the bladder is a bit complex but two centers distal in the spinal cord are involved in the autonomic part of the process, centers that may have been affected by the acute polio. Voiding patterns are however also influenced by factors other than neuro-muscular control. Urine production, bladder capacity, habits, upbringing, culture, practical circumstances and psychological stress also influence voiding pattern. Besides neuro-muscular control all these factors should also be addressed in the work up for patients with voiding problems. In the clinical situation one should start with excluding that diseases other than polio can account for the symptoms. This can quickly be

done by a urinary stick to rule out hematuria and for men a blood sample to test PSA to rule out prostate cancer. Next step is then a drinking/voiding chart and an ultrasound measurement of the volume of residual urine left after voiding. This information can usually indicate whether inappropriate drinking and voiding habits, large urine production at night, abnormal bladder volume or problems with bladder emptying can be part of the problem. If so they should be addressed as part of the solution. For polio patients who have practical problems with getting to the toilet or undressing at the toilet, measures such as better toilet access or a change to clothes than can more easily be taken off (as for example an exchange of buttons with elastic bands) can be of great help. If the above mentioned adjustments are not sufficient to obtain continence, one should carry out a urodynamic study, where the interaction between nerves, bladder muscle and urinary flow is clarified. Information from such a study may lead to solutions such as training of the pelvic floor or special medications. Although there are no reports of bowel problems in relation to polio, it is well known that immobility can cause constipation. Furthermore, some of the above arguments also apply to bowel symptoms. After ruling out other diseases a practical approach is primary to work on getting appropriate toilet habits and adjusting diet. Next step may be to use laxatives and seldom transanal irrigation. Only very rarely there is a need for operations with various variations of colostomies.

#### KL06

### VENTILATION ADVANCEMENTS FOR POLIO PATIENTS OVER THE DECADES

*Anne Duncan, Clinical Nurse Consultant  
Austin Health, Australia*

Historically, methods of artificial respiration were stimulated by attempts at resuscitation. In 1670, John Mayow, an English scientist, came up with the idea for external negative pressure ventilation. He built a model consisting of a bellows and bladder to pull in and expel air. Records from the mid 18th century document a bellows type device as the most commonly used method of providing respiratory assistance. The earliest known body encasing negative pressure ventilator was built in 1832 by Dr Dalzeil, Scotland. This development was followed by a variety of tank and cuirass devices that operated on the principle of enclosing the thorax and using negative pressure to passively expand the chest and inflate the lungs. In 1876 Dr Woillez of Paris built a tank with a manually operated bellows. In 1928 Drs P Drinker and L Shaw made the first widely used tank. It was used successfully in the Boston polio epidemic of that year. In 1931 the Emerson respirator was developed. Simpler than earlier models, it was inexpensive, had a variable rate and could be operated by hand during power failures. The tanks used in Melbourne until a few years ago were essentially the same as all of these. In the 1952 Copenhagen polio epidemic a shortage of tanks resulted in teams of nurses and medical students delivering positive pressure ventilation by hand. They sat by the beds of those with respiratory failure using anaesthetic equipment to ventilate them for days or weeks, until the person no longer needed ventilation. This led to the development of positive pressure machines used in hospitals today. From the ventilators used in hospitals came the development of portable positive pressure ventilators designed for use in the home which became available in Australia in the mid 1980s. The first models used in Australia were volume cycled ventilators such as the LP3 which deliver air until the preset volume is reached. In addition to adjustable volume and rate and sensitivity settings they had high and low pressure alarms and an internal battery. Pressure cycled ventilators such as BiPAPTM (Bi-level positive airway pressure) and VPAPTM (Variable positive airway pressure) machines were introduced in Australia in 1991. They were developed following Dr Colin Sullivan's 1980 invention of CPAP (Continuous positive airway pressure) machines for the treatment of Obstructive sleep apnoea. BiPAP and VPAP machines deliver air in both the inspiratory and expiratory phases of breathing and also have adjustable settings. Some models have alarms and internal batteries.

#### KL07

### TELEMEDICINE OPPORTUNITIES: POTENTIAL HEALTH SERVICE PROVISION AND EDUCATIONAL OPTIONS FOR REMOTE AND/OR DIFFICULT TO REACH POST-POLIO PATIENTS OF ALL AGES

*William DeMayo, Rehabilitation Physician  
John P Murtha Neuroscience and Pain Institute, USA*

Difficulty with access to appropriate medical and rehabilitation services is a common frustration for polio survivors. This presentation will focus on use of technology to address these unmet needs and improve health and wellness. Traditional access points have been physically difficult to negotiate, expensive, and often not focused on the individual need of the polio survivor. Additionally, clinicians with expertise in managing polio related issues have often been hard to find. Telemedicine in general and Telerehabilitation specifically offer new and flexible methods of addressing many of these concerns. Remote monitoring, education, and consultation services can be readily available even to individuals with little technology background. Passive monitoring devices can provide a wealth of information to clinicians. Additionally, new encryption methods allow confidential audio-video and data transmission between clinician and patient/family/caregivers in the home setting using home computer, tablets, or cellphone. Insurance, licensing, and liability regulations are trying to keep pace with this fast growing field which will transform health care delivery over the coming years. As telemedicine grows, it promises to have a profound impact on healthcare delivery for those with disabilities regardless of age, location, or finances. A dramatic impact on future healthcare delivery in developing countries is also anticipated.

#### KL08

### FOUR DECADES OF WORKING WITH POST-POLIO PATIENTS

*Ann Buchan, Neurophysiotherapist  
Unley Physiotherapy, Australia*

From observations of young people wheeling around on barouches or in rigid standing frames when we met for Guide meetings at Yooralla Children's Hospital in Balwyn in the 50's, to seeing a few people still on respirators at Fairfield Hospital where we did our first undergraduate physio year in the mid-60s to the 70's, through to a few people in wheelchairs on a rehabilitation programme at the Austin Hospital, as well as those with spinal injuries. Then jump forward to the 80's when the fatigue, new weakness and pain started to present itself and was dismissed by many clinicians (and still is by some). Only 20-30% of patients at the time would experience these symptoms, so they said, but at least some people started listening to their stories and the other issues being acknowledged – such secondary disabilities as breathing, sleep issues, short term memory loss, and perhaps some post-traumatic stress disorder. What's changed? Better diagnosis? We would not fuse as many joints these days. People without PPS should try standing and balancing with no active toe flexion or extension (mechanical or active)! Individual muscle testing still has value, but does not always show up evidence for the potential of experiencing fatigue (both global and local). Naturally balance and falls risk become more important aspects of assessment with ageing. People requiring the use of more recently made calipers are still not wearing them but hiding them at the back of cupboards. They see them as a retrograde step because of the bad body image and discrimination entrenched during the earlier use of them and they worked so hard to get rid of them – it took 10 years for some to walk without them! New recommendations point to more exercise needed – hydrotherapy or massage for many has been a regular event since the new onset of symptoms but is it enough? (No counselling was available at the time – I suspect there is a need for it now.) There seem to be 10 "P's" of those people with the late effects – amazing



Perseverance, Patience in spite of Pain, education about pain, Picking the right health team, Practical and Psychological support, not Putting everything that goes wrong with the person or body into the Polio Package, and Practising saying no sometimes. The session will discuss some of these changes and points and demonstrate several patient examples.

#### **KL09**

### **SOLUTION BASED TREATMENT OFFERS POSITIVE LIFE CHANGES & NEW HOPE FOR POLIO SURVIVORS**

**Marmaduke Loke, Prosthetist and Orthotist**  
*Bracing Solutions, USA*

Many Polio Survivors are finding New Hope and enjoying Positive Life Changes utilizing advanced bracing methods and technologies. The development of comprehensive standing and walking solutions are proving to offer favorable results. Many people with a history of muscle decline from PPS have had a reversal and are getting stronger, leading to some remarkable quality of life improvements. Several case studies on medical professionals with PPS have shown muscle strength improvement, increased activities, balanced alignment, improved bone density, blood pressure, heart rate, and even running. No polio treatment plan has offered more positive benefits for standing and walking, including related health benefits from human mobility.

#### **KL10**

### **DEVELOPING A LATE EFFECTS CLINIC – WA EXPERIENCE**

**Gnaalechumy Jegasothy, Retired Physiotherapist**  
*Australia*

A session to highlight the imperatives for the setting up of the Late Effects of Disability Clinic/Service, that has the right mix of allied health personnel to meet the future needs of polio clients. A multiple referral pathway to address the problems faced by clients living with the Late Effects of Polio who also face the demands of ageing with a disability. This includes maintaining independence in their own homes, avoiding the path of long term care, and preventing the need for admission into long term residential placement. This presentation will also address the community engagement, research, business case, and protocols required in setting up the Late Effects of Disability Clinic at Royal Perth Hospital – Shenton Park Campus.

#### **KL11**

### **ADVANCES IN THE SURVEILLANCE, CONTROL AND ELIMINATION OF POLIO**

**Robert Booy, Head of Clinical Research**  
*National Centre for Immunisation Research & Surveillance (NCIRS), Australia*

Polio is an acute illness that particularly affects the young, but can hit at any age. It usually causes fever and gastro-intestinal symptoms but rarely (and destructively) in about 1:1,000 cases, can cause paralysis through damage to anterior horn motor cells in the spinal cord. Vaccination is highly effective in preventing disease. There has been a WHO goal since 1988 to eradicate polio from the earth through the concerted and collaborative efforts of many stakeholders including WHO, Rotary, and the Bill and Melinda Gates Foundation. In the last 3 years only 3 countries have had domestic transmission, namely Afghanistan, Pakistan and Nigeria – in 2015, an announcement was made that Nigeria had achieved “elimination”. Focal areas of transmission continued during 2013–15 in a few zones of civil unrest like Syria and Horn of Africa. Ongoing progress will be discussed in the presentation, including the role of different vaccines, the importance of good surveillance for paralysis and the possibility that other enteroviruses may also cause outbreaks where some are left with paralysis.

#### **KL12**

### **IVIG AS A TREATMENT FOR POST-POLIO SYNDROME: TRIAL RESULTS**

**Submitted by Kristian Borg, Professor and Chair**  
*Division of Rehabilitation Medicine, Department of Clinical Sciences, Karolinska Institute, Stockholm, Sweden*

An inflammatory process in both cerebrospinal fluid and peripheral blood has been reported in post-polio patients. It has further been supported by findings of alterations of three proteins, all involved in neuroinflammation and apoptosis. Unfortunately, the inflammatory parameters have not correlated to symptoms or to the course of PPS. The cause of the inflammatory process is at the moment unclear. However, immune-modulating therapy with intravenous immunoglobulin (IvIg) dampens the inflammation and results in an increase of muscle power, increased activity and quality of life especially for vitality as well as for pain. So far no biomarker correlating to a positive outcome of the IvIg treatment has been reported and the clinical experience is that there are responders with a good effect of the treatment but also non-responders as well as negative responders. We are now characterizing the different patterns of response in order to be able to give the treatment to patients who will benefit from it. The hypothesis behind the IvIg treatment has been that the inflammation is of central origin and that high doses of immunoglobulins would be required to pass over the blood-brain barrier. However, recently an up-regulation of prostaglandin enzymes, mPGES and cPGES as well as Cox 1 and Cox 2, was reported in blood vessels in muscle and one may speculate that this may be the background for ‘post-polio pain’ and may be the target for IvIg. This finding indicates that the origin of the inflammation might be peripheral and, thus, opens new possibilities for treatment of PPS.

#### **KL13**

### **COUGH, SPIT AND BREATHLESSNESS IN POLIO SURVIVORS**

**Peter Nolan, General Physician**  
*St Andrews Hospital Toowoomba, Australia*

An overview of the mechanics of breathing will be presented using simple models of the lung as an air pump. The impact of polio on the mechanism of breathing will be detailed. Information relating to the prevalence of respiratory morbidity in polio survivors will be discussed from local Australian data. An understanding of acquired lung diseases involving the muscle pump, the airways and the air sacs will be discussed. Established and new treatments for each of these types of diseases will be presented. Simple guidelines for good lung health will be summarized. *Acknowledgement:* The Toowoomba Polio Support Group.

#### **KL14**

### **MANAGEMENT OF SPINAL ISSUES IN POLIO PATIENTS**

**Carol Vandenakker-Albanese**  
*Physical Medicine & Rehabilitation, University of California-Davis Medical Center, USA*

The spine provides structural support of the trunk and stabilizes the limbs. The polio virus attacks the motor nerves in the spinal cord, resulting in varying degrees of paralysis of muscles. This causes asymmetry of skeletal support and bone, altering posture and function. These changes result in: loss of bone strength, altered body mechanics, secondary deformity, increased stress on spine segments and increased stress on supporting soft tissues. Related spinal problems in the polio survivor include: spinal deformity, osteoporosis, accelerated degeneration, and nerve impingement secondary to spine degeneration that can mimic post-polio syndrome. The risk of scoliosis in a polio survivor is 30%. Progression of the curve is correlated to degree of weakness and age at onset. Bracing is often unsuccessful in preventing progression and surgical fusion is often



recommended. Progression of scoliosis can continue after skeletal maturity due to degenerative changes. Progression can cause an unbalanced spine, bony pressure points, and/or reduced lung function. Polio survivors are at increased risk of osteoporosis based on: reduced peak mass, reduced muscle action on bone, and reduced mobility. Spine (vertebral) fractures may occur with trauma or spontaneously. Spine degeneration is common in polio patients. Stress on the spine is increased by asymmetry of muscle support, postural changes and altered mechanics of movement. Degeneration can include slippage of vertebrae, enlargement of joints and ligaments and bulging discs. Degenerative changes may result in compression of nerves. Single level nerve compression can cause pain, weakness and/or loss of sensation in a limb. Spinal stenosis refers to narrowing of the spinal canal, often as a result of degenerative changes. Symptoms can include: loss of balance and aching in the legs that increases with standing or walking. Pain is usually relieved with sitting or walking with shopping cart or walker and may be confused with symptoms of post-polio syndrome. Medical evaluation is important to diagnose and focus treatment. Treatment options for spine conditions include: postural adjustments, activity modification, physical therapy, medications for pain control, bracing, injection procedures, and surgical intervention. Spine bracing is safe but not always tolerated. Braces reduce motion and provide support. Spinal injection procedures may be very helpful for inflamed nerves or joints. Nerve blocks can help alleviate pain from joint degeneration, but relief is usually temporary. Surgery may be considered when pain or nerve compression results in loss of function. Spine surgery is often major surgery with significant risks. The preferred management of spinal conditions in a polio patient is conservative. Treatment should focus on changes in lifestyle, activity modification and a therapy program that includes postural correction, strengthening, stretching and cardiovascular conditioning.

#### KL15

### DEMYSTIFYING TREATMENT OF THE POLIO BODY

*Melissa McConaghy, Physiotherapist & Practice*

#### Principal

*Advance Rehab Centre, Australia*

Treating people with polio has often intimidated most modern day physiotherapists. This presentation will discuss one physiotherapist's experience of treating people with the LEOp and will elaborate on the current evidence base to demystify the assessment and treatment process of the polio body in an allied health context.

#### KL16

### CASE CONSULTATION: PSYCHOTHERAPY WITH A POLIO SURVIVOR

*Stephanie Machell, Psychologist*

*USA*

This presentation will feature a composite case study illustrating the issues that frequently arise with polio survivors in the initial consultation. Particular attention will be paid to the concepts of resiliency AND resistance in dealing with Post-Polio Syndrome (PPS), how new disability revives the polio experience including any trauma related to it, interactions with "normative" life tasks occurring at the time PPS emerges, and the effects of PPS and the polio experience on the polio survivor's identity.

#### KL17

### THE LEGENDARY WALKER AND UNWITTING BIOMECHANIST

*Bernard Badorrek, Prosthetist and Orthotist*

*Orthomotion, Advance Rehab Centre, Australia*

For many people, living with the effects of polio means an ever-present reality of a compromised or devastated musculoskeletal system and the constant challenge of standing, walking and maintaining mobility. Our polio-affected walkers develop a keen awareness of

the position of their limbs and an understanding of how their centre of mass influences the external forces that act upon the lower limb in order to maintain control, stay upright and walk safely. Compensations are employed to keep the external forces within the critical window of tolerance which are able to be controlled by the individual to stay upright and prevent a fall. Unwittingly, the polio-affected walker becomes an expert in the physics and biomechanics underlying their own condition. However, the reality for these legendary walkers is that all too often these compensations frequently lead to progressive deformities, joint deterioration and overuse syndromes. So after years of managing without, these legendary walkers may seek to use an orthosis to stay on their feet. The orthotist, physiotherapist and physician together with the legendary walker are faced with the challenge of creating a new biomechanical reality, limiting the compensations and overcoming the decline. While the biomechanical principles underpinning gait pathology of the polio-affected walker have not changed, the landscape of orthotic management has changed and continues to evolve. Contemporary gait analysis has had a profound impact on our understanding of gait pathology and the effect of an orthosis on changing the alignment of ground reaction forces and the external moments applied to the joints and limb segments. Previously the exclusive domain of researchers, new and accessible gait analysis techniques integrated into clinical practice are now enabling opportunities to objectify clinical decision making and treatment outcomes. Together with innovation in materials and specialised joint control components the orthotic management of the polio-affected walker is taking on new and exciting directions.

#### KL18

### IMPACT OF OSTEOPOROSIS AND ITS MANAGEMENT IN SURVIVORS OF POLIOMYELITIS

*Nigel Quadros, Rehabilitation Physician*

*Rehabilitation Services, Queen Elizabeth Hospital and Hampstead Rehabilitation Hospital, Australia*

Osteoporosis is defined as a systemic skeletal disorder resulting from an imbalance in bone remodeling. This leads to reduced bone strength and microarchitecture disruption causing skeletal fragility and increased fracture susceptibility. Polio survivors have a predilection to premature osteoporosis at the hip when compared to the general population. This is caused by remnant post-polio muscle weakness and the resulting lack of use of the affected limbs. This results in an increased risk of falls, as well as leading to fragility fractures even with minimal trauma. Such fractures, surgically repaired or otherwise, may often require immobilization over an extended period of time. This leads to muscle wasting and generalized deconditioning as well as an overall reduction in quality of life. Treatment is aimed at preventing fractures as well as reducing future fractures and involves both non-pharmacological and pharmacological interventions. Non-pharmacological interventions target the modification of life style factors such as establishing a balanced diet (containing adequate calcium and vitamin D), the cessation of smoking, the minimization of excessive alcohol consumption and the establishment of a regular exercise programme involving both weight bearing and muscle strengthening activities. Reducing the risk of falls is also critical as it has been reported that 35–40% of polio survivors sustain fractures as a consequence of falls. There are currently no pharmacological interventions to completely reverse established osteoporosis. Treatment is targeted towards halting its progression and, if secondary osteoporosis is present, the treatment of the primary disorder should also be provided. The categories of pharmacological agents include: anticatabolic drugs such as bisphosphonates, estrogen therapy, selective estrogen-receptor modulators, calcitonin and denosumab, proanabolic drugs such as teriparatide or dual-action agents like strontium ranelate. The choice of pharmacological treatment is influenced by patient gender, menopausal status, medical history, whether treatment is for primary or secondary fracture prevention, patient preference and, in Australia, eligibility for government subsidy. As Rehabilitation physicians we should be aware of the increased incidence of osteoporosis in polio

survivors and should incorporate diagnostic and treatment strategies in our overall management of this cohort of patients to both prevent further decreases in bone mineral density and to reduce the risk of fractures. A discussion of osteoporosis and the subsequent risk of fragility fractures and measures to reduce these should be held with patients and their caregivers. Communication and coordination of treatment with the patient's primary care physician is also essential.

#### **KL19**

### **LONG-TERM POLIOVIRUS INFECTION AND ITS POSSIBLE IMPACT ON POST-POLIO SYNDROME**

**Antonio Toniolo, Professor of Medical Microbiology and Virology**

*University of Insubria Medical Center, Varese, Italy*

Is the post-polio syndrome due to chronic poliovirus infection? Over the years, some poliomyelitis survivors may experience a progressive decline of physical strength accompanied by intolerance to cold, chronic pain, other disabilities. The condition, termed post-polio syndrome (PPS), may lead to the incapacity of living an independent life and does generate suffering plus considerable costs. PPS usually arises after many years of partial/complete functional recovery. In developed countries, in fact, it is common experience that polio patients had a productive life before starting to experience PPS symptoms at the time of retirement. PPS is estimated to affect about 20 million people worldwide. Pathogenic pathways that may lead, over time, to the progressive loss of neuromuscular functions are presented. The core message is that PPS might be a consequence of an unapparent chronic low-level poliovirus infection caused by the virus type that - at the time of the initial insult - had infected each patient. The conclusion is derived from the study of over 100 PPS patients and their family members, together with a number of polio survivors with "stable polio". Nearly three quarters of PPS patients appear to harbor "poliovirus remnants" (in other words polioviral genomes and low-level virus activity), while survivors with stable polio rarely harbor poliovirus. The identity of the poliovirus remnants has been clarified by partial genome sequencing. It is thought that chronic virus infection of the nervous and muscular systems may be responsible for low-level chronic inflammation and the progressive loss of neural and muscular cells. A further conclusion of the study is that poliovirus remnants are not transmitted from PPS patients to their family members. Thus, poliovirus remnants appear to be

not dangerous to the population, nor to represent a possible form of resurrection for poliomyelitis. It is assumed, but not proven yet, that the poliovirus forms persisting in polio survivors represent "mutated" or "genetically changed" derivatives of the virulent polioviruses that were circulating at the time of polio epidemics. Finally, the possible infectious etiology of PPS calls for an "effective cure". So far, in fact, anti-inflammatory drugs and other treatments have failed in this field. A possible remedy is seen in the administration of intravenous human immunoglobulins (i.e., antibodies derived from blood donors). Our work brings the attention of clinicians and the pharma industry to the need of antiviral agents for treating PPS. New antiviral compounds are becoming available for picornaviruses, some of them having activity against polioviruses. These novel antivirals might be tested in PPS patients, provided that the industry were willing to sustain clinical trials. Based on therapeutic trials with human immunoglobulins, quantitative methods for evaluating the efficacy of these drugs are already available at a number of clinical centers worldwide.

#### **KL20**

### **POST-POLIO RESEARCH: WHY AND WHAT?**

**Joan Headley, Director, Post-Polio Health International USA**

The post-polio community has been told that "money for research is limited and there are more serious conditions to study," "post-polio research is not sexy," "donors like to fund 'cures,' e.g., the billions for immunizations," "you are aging, get used to it," "there is no research to be done, they just want to make money off of you." Post-Polio Health International (PHI), a non-profit based in Saint Louis, Missouri, USA, has educated, advocated and networked since 1960. In 1995, with a generous bequest from a polio survivor who used a ventilator, PHI added funding and promoting research to its mission. Since that time, PHI has awarded \$395,000 to fund 10 studies. PHI's goal is to provide funding for research that has the potential to improve the lives of polio survivors or users of home mechanical ventilation and to that end its request is not focused on medical studies only (to study the cause(s), treatment and management of the late effects of polio) but also includes the request to explore historical, social, psychological and independent living aspects of living with polio. This presentation will acknowledge the half-truths in the above statements, discuss why conducting post-polio research is important at various life stages, offer ideas for research and challenge groups and individuals to join PHI in promoting and funding research.

## SYMPOSIUM LECTURES (SL01–SL29)

## SL01

### THE LIVED EXPERIENCES OF OLDER PEOPLE WITH POST-POLIO SYNDROME IN AUSTRALIA

*Pat Dorsett, Social Worker, with Sandra Woodbridge, Human Services Professional*

*School of Human Services and Social Work, Griffith University, Australia*

**Introduction/Background:** Major polio epidemics occurred in Australia from the late 1930s until the 1950s affecting many thousands of individuals, with up to 40,000 people diagnosed with paralytic polio. It has been suggested that this may represent only a small percentage of those who actually contracted polio because many non-paralytic cases were not diagnosed. While there is no accurate data on how many people may be impacted by PPS/LEOP, it is estimated that thousands of people may be at risk of developing PPS/LEOP within the Australian population. To date the majority of research has focused on the physical consequences of PPS. However, how PPS/LEOP impacts on the lived experience of those with the condition is less well researched. Emerging research suggests that the impact on one's quality of life and access to supports may be significantly compromised. However, the level of awareness about LEOP/PPS among health professionals and the wider community remains low. **Aims and Research Questions:** To enhance the level of awareness, this study explored the impact of PPS/LEOP on the lived experiences of people with LEOP/PPS in Australia including the impact on quality of life and wellbeing. The following questions formed the basis of the study: 1) What are the life experiences of people with PPS/LEOP in Australia? 2) How has PPS/LEOP impacted on their quality of life and wellbeing? 3) What services or supports are necessary to maintain quality of life and wellbeing? 4) What are the implications of these findings for policy and practice in Queensland and in Australia? **Methodology:** This study adopted a qualitative and interpretive approach, using a mixed method. The sample consisted of people with PPS/LEOP associated with the Queensland Post-Polio Network. Three focus groups and twenty qualitative interviews were conducted in Brisbane and two regional cities in Queensland, Australia. **Results:** This study identifies the resilience and coping strategies embraced by people with PPS/LEOP as well as the many challenges they confront in their everyday life. Despite these experiences many reported a "can do" or a "just get on with it" attitude to life. However, the respondents also faced a number of issues which impacted on their quality of life, including frustration in accessing information, adequate healthcare, and increasing physical limitations. **Conclusions:** The informants' voices presented a strong rationale for appropriate and responsive healthcare and community resources to adequately respond to the increasing numbers of people experiencing PPS/LEOP. This paper will conclude with recommendations for future research, informed by the reality of the lived experience.

## SL02

### LONG-TERM SOCIO-ECONOMIC CONSEQUENCES AND HEALTH CARE COST OF POLIOMYELITIS

*Nete Munk Nielsen, MD, Researcher*

*Department of Epidemiology Research, Statens Serum Institute, Denmark*

A historical cohort study involving 3606 polio patients. **Objective:** To estimate long-term socio-economic consequences and health care cost of poliomyelitis. **Methods:** A historical prospective cohort study including 3,606 Danish individuals hospitalized for poliomyelitis before the age of 30 years, in Copenhagen, Denmark from 1940 to

1954, and 13,795 age and gender matched Danes controls. Information on marital status, parenthood, educational level, employment status, income, usage of the health care system and cost of medicine was obtained from the Danish Civil Registration System and from nation-wide health registers and coherent social statistics. Participants were followed-up from January 1980 until December 2012. Family, socio-economic conditions and health care cost among polio-survivors and controls were evaluated in different age groups using boot-strapped *t*-tests or hazard ratios (HR) calculated in Cox-regression models. All the analyses were performed separately for paralytic and non-paralytic polio survivors. **Results:** Compared to controls fewer paralytic but more non-paralytic polio survivors had been married and more paralytic polio survivors were childless. Paralytic as well as non-paralytic polio survivors were higher educated than controls, and through the ages 30 to 60 years they appeared to have an employment rate only slightly lower than controls, but an income similar to controls. The risk of receiving disability pension was 2.5 fold higher among paralytic polio survivors and 1.4 fold higher among non-paralytic polio survivors compared to controls. Compared to controls, personal health care costs especially due to hospital contacts were much higher among paralytic as well as non-paralytic polio-survivors. **Conclusion:** Individuals with a history of poliomyelitis are well educated, have a slightly lower employment rate, an income similar to the controls, but a considerably higher usage of the health care system.

## SL03

### LONG-TERM MORTALITY AND MORBIDITY FOLLOWING POLIOMYELITIS. A REGISTER CASE CONTROL STUDY OF A COHORT OF DANISH POLIOMYELITIS PATIENTS

*Lise Kay, Urologist*

*Specialized Hospital for Polio and Accident Victims, Denmark*

**Aim:** To describe long term morbidity and mortality in a cohort of patients with poliomyelitis (PM). **Method: Cases:** In the area of greater Copenhagen persons suspected for PM were admitted to the Blegdamshospitalet (now Rigshospitalet). Records from Blegdamshospitalet from 1922–1954 were reviewed to identify patients discharged with a diagnosis of PM (paralytic and non-paralytic). Patients younger than 30 years were found in the Danish Civil Registration System (CRS), a registration system where every citizen since 1968 has been assigned with a unique identification number, a number that is used throughout all official registers. **Controls:** was a cohort of persons matched by sex, age and geographical residence, but otherwise randomly sampled in the CRS. Four controls were sampled for every patient. From the Danish National Patient Register data on hospitalizations and discharge diagnosis (ICD codes) were identified for cases and controls from 1977 until 2013. **Results:** 3,606 patients with poliomyelitis were found. Compared to controls mortality was moderately increased for both paralytic (HR=1.27) and non-paralytic (HR=1.10). Both paralytic and non-paralytic cases were hospitalized 1.5 times as often as controls. Discharge diagnoses represented a wide spectrum of diseases. Diagnoses that do not indicate any obvious disease were more often given to both paralytic and non-paralytic PM patients when compared to controls. **Conclusions:** Both non-paralytic and paralytic survivors from PM have a moderately increased mortality and a 50% increase in hospitalization rate when compared to controls. Diagnoses represented a very broad spectrum of diseases. Diagnoses that do not indicate any obvious disease were more often given to both paralytic and non-paralytic PM survivors, implying a need for more knowledge about the pathophysiological processes that occur in the very long run among survivors from PM.



**SL04****POLIO SERVICES VICTORIA MODEL OF CARE****Yan Chow, Rehabilitation Physician***Polio Services Victoria*

Polio Services Victoria (PSV) at St Vincent's Hospital Melbourne is a State-wide service for clients who have had polio. There is no equivalent service in other States and Territories of Australia. PSV has a full complement of clinicians who provide a multi-disciplinary approach to assess the client and formulate a rehabilitation management plan. The PSV team consists of a rehabilitation physician, physiotherapist, orthotists, occupational therapist, social worker and an allied health assistant. There are metropolitan clinics held at St Vincent's Hospital and some regional cities are serviced. Referral to community based rehabilitation or local health services and involving the client's general practitioner is the most common management. In specific circumstances, some rehabilitation and orthotic management is provided by PSV due to the complexity of the client's condition. There has been an increasing demand for rehabilitation management for clients who have had polio. This has been mostly due to the increase of refugee population and older polio clients have complications related to polio and age-related conditions impacting on polio affected muscles. PSV provides rehabilitation management, advice, support and network clients to local providers. This intervention enables clients to have better self management, reduce complications related to polio and minimise age-related complications. PSV improves community integration and is a unique service to clients who have had polio.

**SL05****A HYDROTHERAPY TRANSITION MODEL FOR POLIO SURVIVORS****Russel Anbiah, Physiotherapist (presented by Dr Yan Chow)***Polio Services Victoria*

Polio Services Victoria is a statewide service offering a multi-disciplinary assessment and referral pathway for polio survivors. The physiotherapy stream at Polio Services Victoria currently offers a 10 week hydrotherapy program for polio survivors. During the 10 week program, patients are assessed and educated on using hydrotherapy as a treatment modality for managing their long-term disability. One of the aims of this program is to integrate patients into the community and support them in managing their long-term disability. After completion of the 10 week program, patients are transitioned into the local community hydrotherapy pools by a clinician. A prospective quality study was conducted to obtain information about this transition process. A total of 17 patients were transitioned through this process. Data collected included patient demographics, use of mobility aids, access into the pool, difficulties faced when attending the local pool, feedback about the exercise session in the pool and also the transition process. A preliminary analysis of the current model suggests that this model is viable and has positive benefits for the patients. The results of this transition process will be analysed further after obtaining ethics approval through St Vincent's Hospital Melbourne. Transitioning patients into a local community hydrotherapy pool for ongoing management of their long-term disability is an important aspect of the self-management model of care for polio survivors.

**SL06****FATIGUE SELF-MANAGEMENT COURSE****Margaret Petkoff, Occupational Therapist***Polio Services Victoria, Australia*

Fatigue is a common symptom of post-polio syndrome. Fatigue can be debilitating and affects all aspects of a person's daily life. Intervention consisted of a referral to the Polio Services Victoria (PSV) Occupational Therapist (OT) for the provision of individual-

ised information on energy conservation, work simplification techniques, and advice regarding adaptive equipment. Information was provided by phone and during a home assessment. Intervention was based on an educational approach, where energy conservation and work simplification techniques were discussed and demonstrated. This approach was not effective. Clients continued to complain of fatigue but did not reduce activity levels or adapt tasks as recommended. Consequently, a self-management education approach for the management of fatigue was developed for a group setting. A 5 week course commenced in 2014. All clients were registered with PSV and were referred by the PSV Rehabilitation Specialist or the PSV co-ordinator. The workshops are based on self-management education principles, specifically on the concepts of self-efficacy, problem solving and education. The focus is on empowering the participants with the knowledge and confidence to make changes to their behavior so that they can manage their fatigue. The workshops are educational and interactive, with an expectation that clients will complete set homework. Outcome measures currently used are the DASS21 and the Fatigue Severity Scale (FSS). Clients are required to complete the DASS21 and FSS prior to course commencement. Three months after course completion, the OT conducts a follow up phone call to all clients to discuss their fatigue management and complete a second FSS. A home visit is offered to clients to address any concerns. The follow up phone call has provided positive qualitative data about the clients' fatigue and activity levels. Clients who have completed the course report significant improvements in their quality of life; improved understanding of fatigue, its management and implications for their daily living; increased knowledge of energy conservation and work simplification principles; barriers to improving their fatigue levels; and improved capacity to set achievable goals. In addition, clients who were previously resistive to adaptive equipment have requested an OT assessment for e.g. scooter assessments and bathroom modifications, whilst others have applied for community assistance, e.g. Council services. Consequently, clients are able to manage their fatigue without compromising their lifestyle.

**SL07****QUALITY OF LIFE AND FATIGUE SEVERITY SCORES OF ATTENDEES OF THE MT WILGA LEOP ASSESSMENT CLINIC****Catriona Morehouse, Physiotherapist***Mt Wilga Private Rehabilitation Hospital, Australia*

Fatigue severity and its relationship with quality of life in an Australian post-polio syndrome population has yet to be reviewed. Reviewing this relationship aims to guide future research and ameliorative strategies for clinicians working with polio survivors. Furthermore, exploring which domains severe fatigue impacts on in regards to quality of life – for example physical, psychological, social function and environmental concerns – may improve our understanding about Post-Polio Syndrome. As part of the multidisciplinary assessment undertaken at the Mt Wilga LEoP (Late Effects of Polio) Clinic from June 2015 to June 2016 approximately fifty (50) consented attendees were asked to complete a WHOQOL – BREF questionnaire and Fatigue Severity Scale. The WHO definition of quality of life is “the individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns.” The WHOQOL-BREF contains 24 scored questions from facets of the 4 domains of physical health, psychological, social relationships and environment and 2 scores of overall quality of life and general health. The Fatigue Severity Scale contains 7 questions and a visual analogue fatigue scale (VAFS). Analysis will be undertaken to identify correlation between fatigue and quality of life domains and other physical or functional findings at the assessment. We hypothesise that severity of fatigue and quality of life are inversely related, particularly in the domain of physical function, and such a finding could enable treatment strategies for polio survivors to be specifically tailored to positively impact their quality of life.



**SL08****HOW NEW BRACING METHODS HELP STRENGTHEN MUSCLES, WHILE REDUCING FATIGUE, AND FALLS***Marmaduke Loke, Prosthetist and Orthotist  
Bracing Solutions, USA*

Triplanar Management, combined with the same prosthetic technologies that enable amputees to achieve high activity, are now possible for polio survivors. These new bracing methods provide better three dimensional alignment of the skeleton, preventing overuse syndromes throughout the body, while enabling a more natural and efficient gait pattern reduces fatigue. This has been proven to allow muscles to recover strength in many polio survivors. Better alignment, designs, and gait patterns have also greatly enhanced balance and stability. Polio survivors have reported a great reduction in falls related to these factors.

**SL09****BEST PRACTICE IN PROVIDING ASSISTIVE TECHNOLOGY AND ENVIRONMENTAL ADAPTATIONS TO THE POLIO COMMUNITY***Natasha Layton, Occupational Therapist and Lecturer  
Deakin University, Australia*

The polio community of Australia actively contributed to The Equipping Inclusion Studies, a 2010 study of the costs and outcomes of assistive technology solutions. This paper presents the findings and conclusions of these studies as well as a related PhD study into disability supports with a specific focus on the needs and lives of those living with the late effects of polio. Key evidence to be presented includes: 1) Measurement of life outcomes and the role of the International Classification of Functioning, Disability and Health (WHO 2001); 2) Contemporary disability theory and the tension between medical/rehabilitative approaches and person-directed approaches as applied to polio and assistive technology solutions; 3) Economic capability approaches and the use of cost consequence analyses to calculate benefits; 4) Evaluating good policy solutions: ways to identify and provide necessary supports using the ISO 9999 Assistive Products for Persons with Disability Standard.

**SL10****ESTABLISHING CONSENSUS OF EXERCISE OPTIONS FOR POST-POLIO***Tim Lathlean, Accredited Exercise Physiologist  
Nillumbik Health Eltham, Australia*

Exercise aimed at improving daily function has been recognised as helpful in managing the late effects of polio since the 1950s (Mead 1950). The general principles for exercise are: 1) A low to moderate intensity (50 to 70% of capacity/ RPE= 4 to 5); 2) Slow progression of increasing intensity, duration and frequency (particularly in affected or de-conditioned muscles); 3) The incorporation of pacing and spacing (rests are to be taken every few minutes); 4) Rotate exercise modes/types and includes stretching/joint range of motion, aerobic or general conditioning (“huffy puffy” activity) and strengthening (also called ‘resistance training’). Exercise as Medicine aims to make physical activity and exercise a standard part of a disease prevention and treatment paradigm in Australia, improving community health and reducing long-term health care costs. More specifically applied to the LEoP, exercise aims to improve muscle function and physical capabilities through energy conservation, improved muscle endurance and strength as well as activities of daily living. Functional tests of physical capabilities have a promising role in helping to identify the prognosis of future effects of polio. Further declines in physical functioning over time depend on an individual’s remaining muscle capacity (Nollet, Beelen et al. 2003). By identifying current

capacities, we can also aim to predict any decline over time in the future. Therefore, exercise physiology is helpful in identifying and mitigating current functional status as well as managing any future decline. Examples of functional tests for identifying physical capabilities in those with the LEoP include: a) The Physical Performance Test (PPT); b) Walking capacity; c) Strength based tests; and/or, d) Other valid and reliable exercise physiology/physical therapy tests. In summary, evidence-based exercise options for post-polio can help improve muscle function and physical capabilities, whilst helping with activities of daily living. In order to ensure the most appropriate exercise-based guidelines, an expert consensus is required that includes the expertise of exercise physiologists in addition to that of medical professionals and other key allied health.

**SL11****SURVEY OF HEALTH PROFESSIONALS WITH EXPERIENCE IN POST-POLIO PATIENT CARE***Joan Headley, Executive Director  
Post-Polio Health International, USA*

In the Spring of 2014, Post-Polio Health International surveyed polio survivors about their polio care received from post-polio specialists and primary care providers. The results were compiled and reported. The goal was to ascertain who used post-polio specialists and their satisfaction with them and equally to explore the care given by primary care physicians. The results demonstrated the preferences of polio survivors in their post-polio management and why, which informed health professionals. The results also demonstrated that there are post-polio patient/health professional relationships that are successful. This PHI survey was designed to explore the actions and opinions of health professionals who are self-identified experts in post-polio care. The survey was distributed electronically to all health professionals in the Post-Polio Directory and to many health professionals who used to be included and are now retired. PHI also distributed to its Members and Association Members asking them to share it with post-polio knowledgeable physicians. Finally, PHI utilized social media to reach as many physicians as possible, who have experience in managing the healthcare needs of the survivors of polio. The results of “the who and the what” of experienced post-polio care will be shared.

**SL12****THE PROFILE OF PEOPLE WITH POLIO/ POST-POLIO ACCESSING THE ENABLE NSW ASSISTIVE TECHNOLOGY PROGRAM***Anna Hartley Orthotist; with Christa Roessler,  
Prosthetist & Occupational Therapist  
EnableNSW, HealthShare NSW, Australia*

EnableNSW is a state-government organisation responsible for providing assistive technology (AT) for people with a disability. As people progress through their life stages, regardless of the underlying disability, it is the experience of EnableNSW that a person’s equipment needs will change over time and often increase in complexity. It is difficult to find clear data describing how many people in Australia are living with the late effects of polio, however EnableNSW has a record of 331 people accessing the program in the five years to July 2015, where their diagnosis was listed as “polio” or “post-polio”. 1794 AT items have been requested for these consumers. The items included respiratory support equipment, continence aids, self-care and mobility equipment, prosthetic limbs, and pressure care aids, although the highest number of requests were for lower-limb orthoses and wheelchairs. This presentation will describe the profile of the polio/post-polio population who access the EnableNSW funding program; a discussion regarding how their AT needs change throughout the life stages; and ways to better access this AT funding program for people with polio or post-polio syndrome in NSW.

**SL13****AEROBIC EXERCISE TRAINING IN POST-POLIO SYNDROME: A PROCESS EVALUATION****Eric Voorn, Researcher***Academic Medical Centre Amsterdam, The Netherlands*

**Introduction:** A recent study (1) failed to show improvements in cardiorespiratory fitness through a home-based exercise program aimed at improving the aerobic capacity through lower extremity exercise in post-polio syndrome (PPS). We performed a process evaluation to explore reasons for the lack of efficacy by quantifying actual training dose and evaluating the effect of the program on muscle function. **Methods:** Forty-four individuals with PPS were randomized to exercise therapy ( $n=22$ ) or usual care ( $n=22$ ). Participants exercised three times weekly for 4 months on a bicycle ergometer ( $> 60\%$  heart rate reserve). We determined the training time spent within the designated target heart rate range, as well as the time at or above the anaerobic threshold (AT). For muscle function, we measured muscle endurance. **Results:** The attendance rate was high (median 89%), but none of the participants trained within the target heart rate range for more than 75% of the designated time. Instead, participants exercised at lower intensities which were around the AT most of the time. We found no improvement in aerobic capacity: muscle endurance (1.6%, 95% CI -10.6 to 13.7) nor cardiorespiratory fitness (submaximal heart rate, -0.3 beats per minute, -7.8 to 7.2) increased in the exercise group, compared to usual care. **Conclusions:** Individuals with PPS were unable to adhere to a high intensity aerobic training program on a bicycle ergometer. Despite exercise intensities around the AT most of the training period, aerobic capacity did not improve. The lack of efficacy on muscle function does not support the assumption of deconditioning of lower extremity muscles in PPS.

Reference

1. Koopman FS, Voorn EL, Beelen A et al. No reduction of severe fatigue in patients with postpolio syndrome by exercise therapy or cognitive behavioral therapy: results of an RCT. *Neurorehabilitation and Neural Repair*, 1545968315600271.

**SL14****EVERY BITE COUNTS – WHY FOOD MATTERS****Melinda Overall, Nutritionist & Lecturer in Nutritional Medicine***Australasian College of Natural Therapies, Australia*

We have more nutrition information at our finger tips than in our history but even as practitioners we are more confused than ever. Nutrition requirements change for us all as we move through different stages of our lives, especially as our bodies age. This talk will focus on the issue of dietary modification for improved longer term health outcomes especially given the considerable number of co-morbidities confronting polio survivors. Without any changes to exercise levels an improved diet may bring with it a myriad of health benefits including but not limited to: improved blood lipid profiles, reduced blood pressure, reduced cardiovascular and cerebrovascular risk, reduced risk of diabetes, improved body composition, reduced risk of mild cognitive impairment and dementias, improved mood and reduced risk of depression, improved immunity and improved bone health. For polio survivors diet is imperative for sustainable long term health.

**SL15****MEDICATION AND THE POST-POLIO PATIENT****Lise Kay, Urologist***Specialized Hospital for Polio and Accident Victims, Denmark*

Effects of medication for comorbidities in Post-Polio Syndrome have not been evaluated in randomized controlled studies. However, this does not necessarily mean that persons with Post-Polio Syndrome respond like everyone else to any sort of medicine. Theoretical considerations and experience indicate that in some areas persons with Post-Polio Syndrome may be at special risk. The acute polio has left polio survivors with fewer nerves in the spinal cord and more central

parts of the nervous system (for example centers for regulation of blood pressure, pulse, and sleep). Furthermore, the remaining nerves may, to some degree, have a suboptimal function. Consequently, medication acting by interfering with nerve-junctions may have a more vigorous effect than normally observed. Various medicines act this way, the most common being in the field of tranquilizers, sleeping medicine, antidepressants, alpha- and beta-blocking agents, and various medicine used for anesthesia. This does not imply that all polio survivors cannot have the above mentioned medicine; it only means that the medicine should be initiated with a low dose, and the patient carefully followed to adjust the dose in relation to the effect/side effects that turn up. Some medicine may have side effects that are more problematic for polio survivors. For example, medicine that is neurotoxic. As polio survivors have fewer nerves, an additional reduction in nerve function may have a much more serious effect than seen in persons with a normal number of nerve cells. Some types of chemotherapy and of antibiotics have this sort of side effect. Various medicines have muscle pain and muscle weakness as side effects. The most common are the “statins” taken for elevated cholesterol level. These side effects seem to occur more often in polio survivors, and with more serious results, as it adds to the symptoms they already experience. The side effects usually disappear within weeks after withdrawal. Pravastatin and Rosuvastatin are reported not to have such side effects. Calcium Antagonists used for hypertension and cardiac symptoms may also result in muscle pain and muscle weakness. In conclusion polio survivors may take almost any form of medicine once the dose is carefully adjusted, neurotoxic medicine however may give permanent nerve damage and should be avoided as far as possible.

**SL16****FALLS PREVENTION****Merete Bertelsen, Physiotherapist***Specialized Hospital for Polio and Accident Victims, Denmark*

Several studies report that polio survivors often fall and experience injuries because of that. Many polio survivors also have fear of falling and these conditions may limit their level of activity and participation in social events. It is therefore important to screen polio survivors for risk of falling, and to facilitate prevention of falling. Much can be done in the home environment, with technical aids, change of habits, bandaging, exercising etc. This presentation will present some screening tools and give inspiration for helping the patient to prevent falling.

**SL17****POLIO EFFECTS MAY JUST BE THE TIP OF THE ICEBERG****Marny Eulberg, Retired Medical Doctor***USA*

The physical effects of prior polio may or may not be obvious but other aspects of the polio survivor's life also need to be considered – for what other conditions does limited mobility predispose a person? What can be done to prevent/ameliorate these risk factors? What about health screenings? Considering a help-mate's health is also important and may affect the ability of the polio survivor to perform daily tasks.

**SL18****SWOLLEN POLIO LEGS****Helen Mackie, Rehabilitation Physician***Mt Wilga Hospital, Australia*

Although polio is generally associated with thin legs due to muscle wasting, swelling and associated heaviness can be a problematic feature, which increases disability and symptom complaints. This talk will discuss the pathophysiology of chronic oedema in polio and the management options for its resolution. Persistent swelling in polio legs should not be accepted as just another consequence of poor mobility – it is manageable and its resolution can result in significant function improvement.

**SL19****PRE-HABILITATION: PREPARING FOR SURGERY**

*Stephen de Graaff, Rehabilitation Physician, Director of Pain Services  
Epworth Health, Australia*

Patients with Post-Polio Sequelae can present a significant challenge when surgery is to be contemplated. With potential pre-existing fatigue, pain and weakness, it makes sense to optimize functional capacity prior to surgery to minimize physical decline post surgery. Prehabilitation, or pre-operative rehabilitation, is the process of enhancing functional capacity of the individual before an operation to enable him or her to withstand the stress of surgery (1). The ultimate aim of prehabilitation is to maintain or improve the normal level of functionality and assist with a quicker rate of recovery of functional status during the period of postoperative inactivity (1–3). It is important to understand the impact of Post-Polio Sequelae, particularly in relationship to preoperative activity and function. Pain, weakness and fatigue increase the likelihood of inactivity along with deconditioning and these will limit the recovery from surgery (4). Education of the patient is essential and areas that need to be addressed include: – Understanding of the surgery and its potential outcomes with prolonged recovery times; – Medications- preoperative, peri-operative and post operative; – Physical functioning, including what is to be achieved prior to surgery; – Emotional wellbeing.

## References

1. Topp R, Ditmyer M, King K, Doherty K, Hornyak III J. The effect of bed rest and potential of prehabilitation on patients in the intensive care unit. *AACN Advanced Critical Care* 2002; 13(2): 263.
2. Ditmyer MM, Topp R, Pifer M. Prehabilitation in preparation for orthopaedic surgery. *Orthopaedic Nursing*. 2002; 21(5): 43.
3. Carli F, Zavorsky GS. Optimizing functional exercise capacity in the elderly surgical population. *Current Opinion in Clinical Nutrition and Metabolic Care*. 2005; 8(1):23–32.
4. Frick, N.M. and Bruno, R.L. Post Polio-Sequelae: Physiological and Psychological Overview. *Rehabilitation Literature*. 1986; 47: 106–111.

**SL20****REHABILITATION FOLLOWING HIP ARTHROPLASTY IN PATIENTS WITH RESIDUAL POLIOMYELITIS**

*Nigel Quadros, Rehabilitation Physician  
Rehabilitation Services, Queen Elizabeth Hospital and Hampstead Rehabilitation Hospital, Australia*

The polio virus predominantly affects the anterior horn cells in the spinal cord. This leads to paralysis of muscle groups in the lower limbs. One, or both, lower limbs may be involved. Paralysis is often asymmetrical. Extensor muscles of the hips and knees and ankles dorsiflexors are commonly affected. Advanced degenerative arthritis of the hip in the paralytic limb, or the non-paralytic contralateral limb, may occur in patients with residual poliomyelitis. Total hip arthroplasty (THA) is a treatment option for some of these patients especially when pain and limitation in mobility affects daily activities and the overall quality of life. There are very few studies regarding THA in this patient group. However, a recent study by Yoon et. al. concluded that THA may be a suitable mode of treatment in adult patients with residual poliomyelitis with persistent hip pain. The authors reported that mild residual pain and persistent leg length discrepancy were complications that required discussion with the patients prior to performing THA especially if it is to be performed on the unaffected limb. The post-operative rehabilitation phase is similar in this patient group when compared to the general population. The goals are to achieve adequate pain relief, improved mobility and ADL's, as well as improvements in the overall quality of life. Patients with residual poliomyelitis have a propensity to develop post-polio syndrome (PPS). The primary symptoms of PPS are pain, muscle weakness and fatigue. An exacerbation of PPS may occur post-surgery and this may, in turn, impact on the rehabilitation phase. In general, patients with PPS may require additional pain relief, a modified exercise program (to limit

fatigue), orthotics and other mobility aids. They may also require a longer period of rehabilitation in the in-patient or ambulatory phase.

**SL21****SLEEP HYGIENE - SLEEP AS A TRAINED BEHAVIOUR. HOW TO IMPROVE DURATION AND QUALITY OF SLEEP TO IMPROVE HEALTH AND WELLNESS**

*William DeMayo, Rehabilitation Physician  
John P Murtha Neuroscience and Pain Institute, USA*

By anyone's standard, the average person today has more "busyness" and less sleep than any time in history. Sleep often becomes a casualty of today's digital technology and media. Most individuals view sleep as a passive state ("falling asleep") rather than an activity ("going to sleep"). Instead of setting a healthy goal of 8 hours or more of sleep, many individuals set a target for sleep just above the point where they cannot function well the next day. Unfortunately, this does not account for the fact that effects of sleep deprivation usually occur over time. Additionally, quality of sleep is often poor due to the effects of stress on reducing percentage of deep sleep so that many individuals have reduction in both quantity and quality of sleep. Results can include chronic fatigue, poor productivity, irritability, weight gain, and exacerbation of painful conditions. In this session we will discuss the topic of Sleep Hygiene – habits that can help anyone take control of their sleep patterns and quality of their sleep. We will look at sleep as a trained behavior. While other circumstances such as pain, children/environment, and medications can all impair sleep, we will focus on the behavioral aspects of sleep that are most under the control of the individual and usually are the limiting factor in obtaining restful sleep over time.

**SL22****ANAESTHESIA FOR THE POST-POLIO PATIENT**

*Christine Ball  
Department of Anaesthesia and Perioperative Medicine, Alfred Hospital and Monash University, Melbourne, Australia*

The patient preparing for a surgical procedure is embarking on a journey, one which will include a large team of people, all focused on the same goal – the complication-free recovery of the patient. The anaesthetist's role in this team is often poorly understood, both by patients and by other health professionals. Not only will the anaesthetist provide a painless route through the surgery itself, but they will also be an important contributor to the optimisation of the patient's health – preoperatively, intraoperatively and postoperatively. For the post-polio patient, communication with the anaesthetist preoperatively is essential. Apart from a general medical and surgical history, the anaesthetist will require specific information about neurological and muscle health, fatigue, sleep disordered breathing, ventilatory requirements and chronic pain issues. They will also perform a focused examination looking particularly at the respiratory system, musculoskeletal deformities and the airway. This interview is an important place for the patient to ask questions and have their particular concerns raised and addressed. The anaesthetist will also communicate with any other health professionals involved in the patient's care. From them they will obtain recent test results, such as respiratory function tests, sleep studies and cardiac echocardiograms, an overall medical history and an understanding of the patient's ongoing treatment plans. Then together they can plan the best possible approach for the particular patient and the most appropriate postoperative monitoring, respiratory care, pain management and rehabilitation. This presentation will explain the issues presented to the anaesthetist when managing the post-polio patient. Given the diversity of the audience, hopefully this will then facilitate improved communication between anaesthetists, patients and the rest of the medical and allied health professional team. The ultimate goal of this talk is improved patient-centred care, allowing each individual patient to feel that their needs are recognised, acknowledged and appropriately managed.



**SL23****FINDING THE RIGHT MASK**

*Anne Duncan, Clinical Nurse Consultant  
Austin Health, Australia*

Finding the right mask to use with non-invasive ventilation (NIV) can be fraught with difficulties. There are many types, models and sizes, each with advantages and disadvantages. The first thing to consider is what type of mask is needed. A full-face mask, nasal mask, nasal pillow systems or a total face mask? There is a bewildering array of models from which to choose. We in the VRSS currently use about 30 different models across all types, each in 3 to 5 sizes. A mask fitting can take from a few minutes to over an hour and you may try a dozen or more before you find the one that is right for your client. The type of mask chosen will depend in part on whether the client is a nose or a mouth breather. If they are a nose breather they may succeed with a nasal mask or nasal pillow system, with or without a chin strap. Some people who are nose breathers when awake may be mouth breathers when sleeping. Others become mouth breathers when receiving NIV, as the natural reaction to the high air flow is to open the mouth to release the pressure. A full face system is often a better option for mouth breathers as it will stop the air from entering via the nose and exiting straight out of the mouth, proving no therapy at all. Whichever mask is selected it should sit comfortably on the face with neither pressure points nor excessive leaks. However, all masks will leak a little as the user moves in their sleep. The machine will compensate for some leak, so there is no need to achieve a perfect seal when putting the mask on. Of course, if there is a leak that is noisy or is blowing into the user's eyes they should adjust the straps slightly or reposition the mask to reduce the leak. "Stubble means trouble", a poor mask seal, excessive leak and inadequate therapy. Men who use NIV therapy should shave regularly to help achieve a good mask seal. Skin care is important when a mask is worn for hours at a time. We recommend that the user begins a twice daily skin care regime. Over-tightening the headgear is the most common error we see when visiting our clients. As it can result in a pressure sore on the nose it is to be avoided if at all possible. Good maintenance of the mask and headgear is essential. Poorly maintained masks can smell bad and don't seal well. This often results in excessive leak, inadequate therapy and reduced life of the equipment.

**SL24****POSTURE AND MUSCULOSKELETAL PAIN**

*Carol Vandenakker-Albanese, Physical Medicine & Rehabilitation*

*University of California-Davis Medical Center, USA*

Posture is the way in which your body is positioned when you are sitting or standing. It is determined by multiple factors including: skeletal anatomy, muscle function, joint function, connective tissue, weight distribution, genetics, habits and pain. Because of the asymmetrical effect of paralytic polio, many polio survivors live with significant muscle imbalance. This muscle imbalance results in uneven growth of bones and wear and tear on joints. Weak muscles provide poor or uneven support of joints and changes in joint and/or spine alignment. In association with lax or tight tendons, ligaments and connective tissue, body mechanics are altered. Good posture has multiple benefits to musculoskeletal health. It keeps bones and joints in the correct alignment so that muscles are being used properly. It helps decrease the abnormal wearing of joint surfaces that could result in arthritis and decreases the stress on the ligaments holding the joints of the spine together. It can prevent the spine from becoming fixed in abnormal positions. Correct posture and body mechanics can reduce or prevent fatigue because muscles are being used more efficiently, allowing the body to use less energy, prevent strain or overuse problems, and prevent backache and muscular pain. Perfect posture may not be realistic, but simple postural changes can result in health benefits. This session will discuss postural goals and the strategies that can be used to achieve improved posture and body mechanics.

**SL25****SERUM CARNITINE LEVELS: A USEFUL INDICATOR TO DETERMINE EFFECTIVENESS OF L-CARNITINE SUPPLEMENTATION AS A CLINICAL TREATMENT FOR POST-POLIO FATIGUE**

*Tessa Jupp, OAM, Registered Nurse  
Polio Clinic WA, Australia*

A 20-year original longitudinal study of serum carnitine levels undertaken on Western Australia polio survivors to assess the effectiveness of supplemental L-carnitine as an ongoing clinical treatment for the fatigue, muscle pain and lack of endurance commonly experienced in post-polio. Information on the role of carnitine in muscle energy production has been available in medical textbooks since 1970 and many more recent published research papers are on the internet. This current study documents feedback from patients who have experienced an improvement in symptoms and serum results that show a positive change. Two case studies are included. Initial interest in the possible application of L-carnitine supplementation for post-polio symptoms was inspired in 1994 when WA Polio Clinic Supervisor, Tessa Jupp RN, on listening to a recording of a then recent presentation on L-Carnitine by Richard Kunin MD, at the 1994 International Nutritional Medicine Today Conference in Canada, realised that the symptoms of carnitine deficiency were very similar to those of LEO-P. Jupp found that this conclusion was further supported by published work she had read on post-polio muscle fibre morphology by Prof Kristian Borg MD PhD, showing a dominance of type I muscle fibres post polio and David Moffett, PhD Biology, on experimental muscle type changes with cross innervation. This documented process was likely to have occurred in the initial recovery post acute polio. After initial patient supplement trials in 1994–95, a small double-blind pilot study was undertaken in 1996 under the direction of John Niblett MBBS, FRACR, FACHPM, Hon Med Officer, Polio Clinic WA and Prof Barrie Finin BPharm, PhD, PhC, FPC, Pharm Dept, Monash Uni, Melbourne. This study included serum carnitine levels processed by Dr Garth Wilson at Biochem, Princess Margaret Children's Hospital, Perth, who instructed Jupp in performing the initial analysis of the serum results from WA polio survivors. As the variation in serum carnitine levels was found to clearly correspond with patient perceived symptomatic improvement, it was elected to continue the on-going study using serum levels to confirm an effective dosage-regime for individual polio survivors to benefit from this research on oral L-carnitine supplementation. A more recent re-survey of serum levels of long-term WA L-carnitine users will be included in the presentation. The results of a small study on L-carnitine by Dr Thomas Lehmann in Switzerland were made available in 1994. Jupp and Lehmann have continued to correspond on their findings over the past 20 years. Lehmann, a polio survivor himself, and his post-polio patients have also continued to use L-carnitine successfully for more than 20 years, as have WA polio survivors.

**SL26****POLIO AND PPS: CHANGING IDENTITIES**

*Stephanie Machell, Psychologist  
USA*

The polio experience became part of the survivor's identity. For all polio survivors, but especially for those who were able to pass as nondisabled, PPS may precipitate an identity crisis. As "use it or lose it" becomes "conserve to preserve," aspects of identity that were based on the ability to push through and overcome are called into question. This talk will address the importance of addressing issues of changing identity, including self-perception and identification with the disability community, grief over lost abilities and roles, and ways the original polio experience may be revived as the survivor works through these issues.



**SL27****POST-POLIO SYNDROME: UNANSWERED QUESTIONS**

**Frans Nollet, Professor in Rehabilitation Medicine**  
*Academical Medical Hospital, The Netherlands*

Despite the large amount of research on post-polio syndrome (PPS) since the mid-eighties of the previous century much about PPS is still unknown. Until now, we do not precisely know the cause of PPS, who are at risk, what influences the rate of decline, how it compares to normal aging and finally, the evidence for the effectiveness of therapies is scarce. Over the past years, evidence has become available for a chronic systematic inflammation and inflammation in the cerebrospinal fluid of patients with PPS. How this influences the decline in muscle function is however not clear. A recent study found no relation between systematic inflammation and rate of decline over 10 years. The slow rate of decline in muscle function has been demonstrated in a number of studies, some with long duration. There is however a lack in studies that included a matched control group of aging individuals with no history of polio. This makes it difficult to conclude whether polio survivors decline faster due to normal aging or that PPS symptoms and functional decline are mainly the consequence of the lack of muscle capacity that resulted after recovery from the acute polio, and further declines in line with normal aging. There is recent evidence that the rate of decline in muscle function is related to the extent of motor unit enlargement as compensation for the loss of motor neurons. The large intra- and inter-individual variation in distribution and severity of polio affection and recovery, and compensations in movement patterns makes it extremely difficult to identify prognostic factors and to predict the individual course. The update of the Cochrane review to treatment for PPS as published in 2015 concluded that no definite conclusions can be made to the effectiveness of any interventions due to insufficient good-quality data and scarcity of randomised studies. Given the large number of around 20 million polio survivors worldwide, further studies to PPS are warranted. It would be very valuable to set up large, international prospective cohort studies, which include 'healthy' aging controls, that are followed for many years. Such studies can provide much information

on rate of decline in muscle function and in functioning and the risk factors. By adding measurements of inflammatory markers, fatty infiltration of muscles and motor unit organisation better insight in PPS can be gained. Furthermore, more clinical trials of interventions should be undertaken. At present, the FORCE trial, a large international multicentre study to immunoglobulins is being conducted. Besides this, methodologically rigorous studies to multidisciplinary rehabilitation interventions are needed.

**SL28****THE DIFFERING NEEDS OF YOUNGER POLIO SURVIVORS**

**TBA**

**SL29****SOPHISTICATED BRACING SOLUTIONS OFFER IMPROVED LIFE CHANGES**

**Bruce (Mac) McClellan, CPO**

*Prosthetic and Orthotic Associates, USA*

Developing sophisticated bracing solutions offers great advantage over conventional bracing. Advanced bracing solutions enable better posture, trust, mobility, efficiency and function. The brace is only a part of the overall solution. Comprehensive solution development is based on assessing a plethora of issues not recognized before that affect efficiency and mobility for the polio survivor. These advanced bracing methods have enabled many people to stand longer, walk farther, improve muscle strength, and for some, even run with paralyzed limbs. Topics included in the presentation: Reversal of Muscle Weakness, Overuse Syndromes, Bone Density, and Pain. Energy Efficiency, Harnessing Gravity, Triplanar Alignment, Minimizing Compensatory Patterns, Overuse Syndromes, Designing to enable more efficient patterning, Trust, Security Issues, Better Support systems. Allowing balanced relaxed Hands-free Standing, orthotic training, and enabling walking with less energy.

**FREE PAPERS (FP01–FP14)****FP01****THE BENEFITS AND DANGERS OF SOCIAL MEDIA IN THE CARE, TREATMENT AND MANAGEMENT OF POST-POLIO SYNDROME – AN OBSERVATIONAL STUDY**

**John R. McFarlane, President** (presented by Gillian Thomas)  
*European Polio Union, Ireland*

The phenomena of social media has caused an explosion of realisation of the problems being faced amongst world-wide communities of polio Survivors, in particular those of the recognition of Post-polio Syndrome. Facebook and Twitter, especially, have spawned a plethora of on-line support communities that concentrate on the problems, medical, social and economic, that affect the different and differing groups of polio Survivors, their families, and carers. Discussions range across many topics including life style choices and solutions, orthoses and their comparative use, comparisons of health systems as well as medical discussions where polio Survivors discuss the merits, or otherwise, of medical practitioners, the lack of medical awareness in the medical community and in many cases on-line discussion of the particular polio Survivor's problems in the care, treatment and management of Post-polio Syndrome in the Primary care environment. This approach to peer support is having great benefits with this wide ranging information exchange often across continents but it has also highlighted many dangers and drawbacks whereby polio Survivors demonstrate a trait to lay the blame for all complaints on Post-polio Syndrome. This study, drawn from observation and case study over a defined 12-month period covering peer support groups, moderated and un-moderated, based in Europe and the USA, will show how the use of social media (Facebook, Twitter etc.) can enhance the quality of life and independence of the polio Survivor. How its use may be utilised by medical personnel from all disciplines regarding care, management and treatment; as well as how dangers of mis-information from any source, both accidental and intended, may be avoided. It will also address the necessity for moderating peer support groups, reliance on single source authority and the growing problem of "devotees" gaining access to peer support groups and preying on polio Survivors both financially, psychologically and sexually.

**FP02****UNIVERSAL DESIGN: BEYOND THE ACCESS CODES**

**Jane Bringolf, Community Services**  
*Council on the Ageing NSW and Centre for Universal Design Australia*

Universal design is a design process that is inclusive of a diverse population. The aim of universal design is to improve human performance, health and wellness, and social participation. It is a process of thinking and designing inclusively, whether it is a house, website, product, service, or a learning program. Universal design is itself explained in a diversity of ways across the world: "design-for-all" and "inclusive design" are other terms used. As an international movement, universal design is cited in the WHO Age Friendly Cities program and the UN Convention on the Rights of Persons with Disability as the means by which to create greater social and economic inclusion. Australian state and federal policy documents also recognise universal design as the way to progress the inclusion agenda in Australia. However, the term "universal design" suffers from many myths and misunderstandings. It is often assumed to be the same thing as access, accessibility, universal access, adaptable housing, universal housing, and in the worst case scenario, "disabled design". Nowhere is this more apparent than in many national and state policy documents where "universal design" is added into a paragraph without reference to what it is meant to achieve or how to achieve it. The Disability Discrimination Act brought about basic access codes which have improved matters in the public built environment. Most people with post-polio have lived through this time of change. However, for someone with post-polio, the notion of "active ageing" takes on a dif-

ferent meaning to those who have enjoyed good health throughout life. For people with post-polio the move to a more inclusive world is still elusive but essential if they are to continue to be active. We still have a long way to go with housing design, websites, and industrial design. Physical access to a building is just the beginning. What happens at the reception desk, how information is presented in brochures and on websites, and how services are designed are critical to the delivery chain of inclusive practices. Universal design thinking makes the links because the experience of the user is considered, whereas access codes focus on the compliance checklist that needs to be signed off by a certifier. One of the principles of the classic 7 Principles of Universal Design is that things are easy to use. Some would argue that universal design itself is not easy to understand and apply. Yet, others who understand the concepts say it is simple – once you understand the concept of inclusion. This presentation will cover the updated principles of universal design, discuss the myths that hold us back, and what action we need to take.

**FP03****LEOP: CLINICAL PRACTICE WORKSHOP SERIES FOR ALLIED HEALTH PROFESSIONALS**

**Mary-ann Liethof, National Program Manager**  
*Polio Australia*

It is hoped that in coming years polio's late effects will become more understood and better treated as polio survivors around the world age, and begin to experience the Late Effects of Polio (LEoP) and its subset, Post-Polio Syndrome (PPS). Australia is at the forefront of raising awareness amongst health professionals of the best assessment and care methods for clients now living the second chapter of the poliomyelitis story for our polio survivors, and for those who are still contracting the disease in the global community. Although it is evident that the thousands of Australians who survived the polio epidemics of last century are now experiencing the LEoP and/or PPS, and a host of comorbidities as they age, there is a paucity of health professionals who can recognise and effectively manage the condition. In 2014, Polio Australia ran a successful pilot Post-Polio Clinical Practice Workshop in Victoria, the purpose of which was to determine the level of knowledge amongst health practitioners regarding the LEoP and PPS, and if they believed wider training was warranted amongst their peers. The 20 multi-disciplinary health professionals who participated unanimously reported that more training was required, and agreed that whilst there are many cross-overs in the treatment and management of other chronic diseases and the management of the LEoP, there are also some very significant differences. In 2015–16, Polio Australia partnered with Rotary District 9685 to run a series of 8 Post-Polio Clinical Practice Workshops for approx. 140 health professionals in the northern Sydney region. Attendees completed a short Evaluation at the conclusion of each Workshop and received a Certificate of Attendance, accounting for 2.5 CPD hours. After completing their training, participants were also invited to add themselves to Polio Australia's Health Professional Listing on the Polio Health website. Through this Post-Polio Clinical Practice Workshop series, Polio Australia has built a complement of skilled and knowledgeable 'post-polio' practitioners across many different modalities around Sydney. The long term goal is to use the Clinical Practice Workshop series as a model for rolling out this post-polio education program nationally, thereby further increasing awareness and standardising healthcare provision for Australia's polio survivors.

**FP04****A PERFECT STORM? SALK VACCINE SHORTAGES AND THE POLIO EPIDEMICS IN AUSTRALIA**

**Kerry Highley, Medical Historian**  
*Australia*

Immunisation against poliomyelitis using the Salk vaccine produced by the CSL in Melbourne began in Australia in June 1956. Almost

as soon as the campaign began, it became evident that the demand by Australians for the vaccine would exceed supply. Politicians blamed the immunising authorities for promoting the campaign to inoculate Australia's children as a race against time, thus resulting in a mad scramble for the limited amounts of vaccine that CSL could produce. Against a background of well-publicised shortages of the Salk vaccine, notifications of poliomyelitis in Australia began to rapidly decline over the next four years. However, in 1960 notifications began to rise, reaching a peak with an epidemic that appeared in Wollongong, NSW in May 1961. What is significant in the context of this outbreak is that no Salk vaccine had been available Australia-wide for the previous seven months.

#### FP05

### BRACE YOURSELF: THE POLIO EXPERIENCE AS VISUAL LANGUAGE FROM A DAUGHTER'S/CARER'S PERSPECTIVE

*Danica Knezevic, Artist*

*Sydney College of the Arts, The University of Sydney, Australia*

The basic needs of others are fundamentally important but cannot be achieved individually. The ever-changing understanding of self remains in the essence of being present to these experiences. Mirroring and reflecting creates a rhythm for a song that we all move to. This rhythm is not always heard or seen but inhabits the experience of our many selves. My mum developed polio at 18 months of age and, in her later years, post-polio syndrome. I have inherited an understanding of her rhythm and her changing rhythm, and it has danced through my art process since I began to practice my art making. In this presentation, I intend to speak about my artworks and my experiences as a daughter of someone with post-polio, as a carer and as a woman. This has provided an inbuilt awareness of other's needs, and the symbiotic relationship that has formed my art making practice, through attachments. Part of my current research is investigating Heinz Kohut's theory, who developed Self-Psychology. Kohut determined that mirroring, idealising and twinship were selfobject functions that a therapist provided to develop a conscious self. He applied empathy to these functions that were necessary when dealing with individuals, to re-affirm the self. This research has helped me identify a separation and a fragmentation of the self: the self as a carer, negotiating the needs of others, while negotiating my own self-needs. I have called this, The Dissonance of Self. My practice is inspired by the individual's search for self and identity: what lies between visibility and invisibility. I express this search through performance, audiovisual installation, photography and drawing. My practice is informed by psychology to examine the intimate relationships within the self. My own history, familial experiences and cultural heritage inform my work: questioning my origin and expressing these as self-reflective conclusions. I believe that we cannot know the self without having a mirror (selfobject experiences) that mirrors our internal experience. By using the body and the objects that occupy my world, I find meaning and create an experience through a tangible self.

#### FP06

### FINDING ME: BEING ABORIGINAL AND ILL IN AUSTRALIAN SOCIETY IN THE 1950S AND 60S

*Gayle Kennedy, Author*

*Australia*

I got polio in 1957 and went to hospital in Sydney and then rehab also in Sydney and, consequently, did not see my family until 1961. I had completely forgotten my family and had no idea was Aboriginal, let alone black. Australian society at the time meant that my parents could not have travelled to see me without specific permission and a special licence called a dog tag. They were also very poor so I did not see them until 1961. I spent the next 9 years going back and forth between my family and the Far West Home and as a result grew up extremely confused about just where I belonged. I will talk about the effect it all had on not only me but my family and how I finally went home and discovered my heritage. I want to talk about the profound effect polio had not only on me but also my family and what it meant

to be Aboriginal and ill in Australian society in the 50s and 60s. I will also talk about how I am learning to live with post-polio syndrome and the effect it has on meeting my cultural obligations.

#### FP07

### QUALITY PATIENT CARE – THE POLIO SURVIVOR'S PERSPECTIVE

*Liz Telford, Social Worker & Polio Health Advocate*

*Railway Place Therapy and Consulting, Australia*

Living with post polio requires the person to learn about the condition and what is needed to adapt to its challenges. However, the knowledge gained is rarely used for the planning and provision of polio healthcare. Drawing on this knowledge, Post-Polio Victoria (PPV) is advocating for improvements, which will reduce medical complications and encourage greater patient engagement with rehabilitation programs. PPV's research has drawn on current literature as well as anecdotal evidence from PPV members identifying five crucial areas that require health care improvements in hospitals, rehabilitation services and government support. Rehabilitation treatment models that avoid the didactic doctor-patient relationship of the medical model have been found to be more effective when dealing with chronic illness (Adrian E Bauman, H John Fardy and Peter G Harris; 2003; 179 (5): 253–256). This is supported by local anecdotal evidence. In hospitals, the risks for patients with a history of polio when admitted to hospital for surgery are well documented (Lambert DA, Giannouli E, Schmidt, BJ 2005;103:638–44). Despite this knowledge, the onus is on the patient to inform the hospital of their polio history, its effects and the implications when undergoing surgery and associated medical interventions. Local recent examples will illustrate this. Government disability funding in Australia is going through a revolutionary change with the introduction of the National Disability Insurance Scheme. While younger people will benefit, those over 65 will not. The five improvements recommended are the use of a patient-centred model of rehabilitative care, increased polio awareness for doctors and allied health professionals, polio appropriate respiratory testing in hospitals and rehabilitation, relevant hospital protocols for the treatment and management of the patient with a history of polio and the adequate funding of aids and equipment, and other care needs for people of all ages living with polio. This paper recommends actions to reduce medical and surgical complications and improve health outcomes and recovery rate for those with post-polio.

#### FP08

### BUT HOW MANY OF YOU ARE THERE?

*Gillian Thomas, Vice-President, Polio Australia*

*President, Polio NSW, Australia*

Many Australians experiencing the late effects of polio are undiagnosed, under-diagnosed, or misdiagnosed. To raise awareness of the condition and assure earliest diagnosis, appropriate treatment, and proper care management, a large-scale awareness campaign must be conducted throughout Australia, together with training for health professionals in the diagnosis and management of the late effects, and education for polio survivors to assist them to self-manage their condition. Such an ambitious program requires resourcing. The first question always asked by potential funders is "How many polio survivors are there in Australia?" Unfortunately, this is a much easier question to ask than to answer – for several reasons, there is simply no definitive number available. Although polio became a notifiable disease in Australia in 1922, records were poorly maintained and many cases were either not reported at all, or misdiagnosed and reported as illnesses such as encephalitis or meningitis. In some years (for example, the war years), and in some areas (for example, the Northern Territory), reporting was very patchy. In addition, a great many hospital records from the epidemic years were simply destroyed in accordance with practices of the time. Finally, many people who contracted polio during the epidemics may be unaware of their infection, but still at risk of experiencing the late effects (for poliovirus damage to be visible as weakness or paralysis, at least 50% of the nerves controlling muscular action must be damaged or destroyed). The need for a credible record of polio survivor numbers



has long been apparent, but there were no financial resources available to pay for the establishment and maintenance of a survivor register, or to commission an epidemiological study. Undaunted, Polio Australia set up the web-based Australian Polio Register (APR) in 2010. Polio survivors were recruited from the membership of all state polio networks and encouraged to add their details to the APR. Being web-based, and promoted by the polio community, the Register has also been very successful in making contact with many polio survivors who previously had not connected with their peers – almost 50% of those registering were not members of a state or local support group, with most being unaware such groups existed. The APR is therefore not only gathering information on the number of survivors living in Australia today, but is assisting those previously hidden in the community to become informed about the late effects of polio and their management. As well as quantifying polio survivor numbers, the APR is also assembling a rich data set of related information. The ability to inform government policy development and facilitate provision of long-overdue funding and services is at last becoming a reality. This presentation will detail and explore what has been learned from registrations to date.

#### FP09

### AGEING SUCCESSFULLY WITH A LONG-TERM DISABILITY: INSIGHTS FROM AUSTRALIAN POLIO SURVIVORS

*Nicola Heath, PhD Candidate*

*Melbourne School of Psychological Sciences, University of Melbourne, Australia*

The dominant model of successful ageing states that to age well older adults must be free of disease and disability, maintain high levels of cognitive functioning and remain actively engaged in life. According to this model it is therefore not possible for people with a long-term disability or impairment such as post-polio syndrome to age successfully. This is important because, despite concerns that the current model ignores and encourages the marginalisation of those ageing with disabilities, international governments have increasingly turned to the successful ageing research to help form policy responses that aim to limit the future burden of caring for an ageing population. Early studies have however shown that the avoidance of disability or illness is not predictive of subjective assessments of successful ageing and that the current model fails to capture key adaptation and coping processes. There is therefore a need to better understand what successful ageing means to people who are ageing with a long-term disability. *Aims:* To gain a better understanding of what successful ageing means for individuals experiencing post-polio syndrome and to identify the factors that are important for ageing well in order to inform effective interventions and recommendations that can assist people with a disability age well over the long term. *Methodology:* A purposive sampling model was used to recruit nine older adults (8 female and 1 male) aged between 60–78 who had polio in childhood and who are now experiencing post-polio syndrome. Semi-structured interviews were conducted to increase understanding of ageing and adjustment experiences and help identify factors that participants identified as stressors and obstacles to ageing well. The main areas explored in the interview were: – Perceptions of ageing and what it means to age well. – Perceptions of factors considered important for ageing well. – Satisfaction with ageing. – Positive aspects of ageing with post-polio syndrome. – The obstacles that negatively affect the experience of ageing with post-polio syndrome, including the nature of stressors experienced and their impact on wellbeing. Interviews were audio recorded and transcribed for subsequent thematic analysis. *Results:* A more nuanced definition relating to health and physical functioning than that proposed by the current model was found. Three potential new factors (independence, respect and security) were also elicited which may contribute additional understanding of ageing success in the context of disability. *Conclusions:* The results of this study have implications not only for the current model of successful ageing and its applicability to individuals who have experienced long-term disabilities, but also to future healthcare and government services. This paper will also outline additional quantitative research that aims to build upon the findings of this study in a larger and more diverse sample.

#### FP10

### THE ‘GOLDEN HOUR’ FOR RISK SCREENING AND INTERVENING TO PREVENT PRESSURE ULCERS POST-POLIO

*Catherine Sharp, Founder & CEO*

*The Wound Centre, Australia*

Post-polio syndrome (PPS) symptoms may include fatigue, muscle weakness and decreased mobility. Decreased mobility renders people at risk of developing pressure ulcers (PU), an ischaemic process, if they are unable to reposition themselves to relieve pressure. Pressure ulcers are very painful and can lead to sepsis, amputation of limbs and death. Being unable to reposition, roll from side to side, results in unrelieved pressure on tissue leading to PU development. Patients are screened on admission to any healthcare facility and this is important because PUs can begin in as little as one hour and healthcare workers need to know if the patient is at risk and provide an alternating pressure air mattress (APAM) in a timely manner. An APAM will relieve pressure on all parts of the body, every few minutes, 24/7. If staff don't provide one immediately, the patient should ask for one. The consequences of leaving any patient in one position for hours before screening, then intervening, are dire even though the time for onset of PUs is not exact but a range of probable times. Evidence, and common sense derived from experience of patient care, suggests that screening and intervening should occur within the first hour. When patients present with symptoms of stroke, another ischaemic process, the ‘golden hour’ concept is applied because hyper-acute therapy is known to be more effective than later intervention. Screening patients on admission, using clinical judgement, focusing on immobility, the only evidence-based risk factor for PU development is the fastest way to determine risk. Intervening within the first ‘golden hour’ will prevent PUs and is the foundation of PU prevention.

#### FP11

### PROGRESS TOWARDS ESTABLISHING POST-POLIO CLINICS IN NEW ZEALAND

*Julie Rope, Physiotherapist, Rope Neuro Rehabilitation with Gordon Jackman, Program Manager, Polio NZ*

*New Zealand*

Until recently polio survivors in New Zealand have had little support to either be assessed for the Late Effects of Polio (LEoP) or develop clinically robust rehabilitation plans. In 2015 Polio NZ developed a strategic plan with the development of polio clinics in NZ as a major goal. Gordon Jackman was hired by Polio NZ in November 2015 to implement the strategic plan. At the same time the Sir Thomas and Lady Duncan Trust, founders of the Duncan Polio Hospital in 1945, had initiated a process with Julie Rope of Rope Neuro Rehabilitation of Newmarket, Auckland with similar aims. Polio NZ, the Duncan Trust and Julie Rope got together and developed a plan to create a clinical support network in New Zealand for polio survivors, wherever they were, to enable them to access expert assessment and supported rehabilitation plans, as well as ongoing support for them and their families. This initially would involve polio clinics in Auckland and at QE Health in Rotorua, with further clinics planned for Wellington, Christchurch and possibly Dunedin. Connecting all these clinics will be a virtual centre of excellence which will share resources, co-ordinate the training of clinicians and health professionals, and resource support in the home. Conducting clinics in remote areas is also an aim, as many polio survivors have great difficulty in travelling to main centres. Measures taken so far include initiating an epidemiological study of polio survivors in New Zealand with Auckland University of Technology to inform realistic discussions with District Health Boards (DHBs) on the provision of services. We have met with Ministry of Health (MoH) officials in Wellington about our proposals, receiving a very understanding hearing and ongoing support. Applications have been submitted to The MoH “Mobility Action Plan” for the development and delivery of services to polio survivors by QE Health in Rotorua and Rope Neuro Rehabilitation in Auckland, which has already independently started funded assessments in its Auckland based clinic. Polio Australia hosted Julie Rope at an



“Understanding the Late Effects of Polio Clinical Practice Workshop” at Mt Wilga Private Hospital so that she can deliver the workshops in New Zealand and in the future develop educational resources and webinars. Catriona Morehouse from Mt Wilga has been very generous in sharing her experiences with us. Other steps have included meeting with DHB directors to establish current DHB’s level of provision for polio survivors with the LEOp and opportunities for collaboration in the future. Contact has been made with Physiotherapists and Occupational Therapists across NZ centres to establish a Neuro Special Interest Group for polio treatment and assessment supported by the virtual centre of excellence. Progress has also been made with Universities and Polytechnics to include LEOp in the curriculum.

## FP12

### PRODUCING THE UK PPS MANAGEMENT GUIDE FOR HEALTH CARE PROFESSIONALS

*Frances Quinn, British Polio Fellowship Expert Panel Member*

*United Kingdom*

The British Polio Fellowship (BPF) support services receive thousands of queries from UK polio survivors seeking management advice for the medical professionals. The Fellowship has commissioned surveys which show that GPs and the general public both have a low awareness of PPS. In response to this issue, the BPF Expert Panel was asked to develop guidelines to help the health care community look after people experiencing the sometimes devastating effects of PPS. The aim was to provide a resource for primary health care - this sector is the first port of call for medical help and provides many of the interventions required by people with PPS. Why a UK PPS guideline? In order to put a strong case to the UK medical community, it was important to detail the UK context such as the demographics of UK polio survivors, and to present the recommended multi-disciplinary management in terms of the UK health service model. BPF members regularly report not only their medical professionals’ limited knowledge of PPS, but sadly, on occasion, a lack of acceptance that PPS exists. For this reason, the guidelines provide an evidence-based review of the pathology of PPS and its characteristics, along with detailed references to studies of the symptoms. This presentation will give an account of how these guidelines were developed in response to BPF members’ current problems with medical treatment. In line with the conference goals, the guidelines fill a gap in the clinical management of PPS by summarising the latest research on PPS and communicating it in a readily accessible format for a wide range of non-specialist health professionals. Quick-reference checklists for assessment and interventions are included to aid treatment along with necessary precautions and appropriate onward referral. It will also review the key information sources and highlight what helped the process, along with the difficulties encountered. Looking to the future, the guidelines will be accompanied by a quick reference guide for professionals, a short version for polio survivors – other possible supporting documents will be discussed.

## FP13

### HOW THE POWER OF ONE ACHIEVES INCLUSIVE COMMUNITIES

*John Mayo, Chief Advisor, Government*

*Spinal Life Australia, Australia*

Inaccessible venues, services and paths of travel lock people with diminished function out of life. Yet there is law that all people should be able to participate in the community and be a customer in the community. One person or group using strategic advocacy can achieve accessible, inclusive communities provided they use key stepping stones. Easy success may come from asking the owner of the problem for leadership – but more often it requires an understanding of the players on the chessboard and the social and economic impacts. For example, Highway 1, Australia’s principal road carrying the nation’s traffic, runs through the main street of a North Queensland sugar town of 3,000 people. There are shops, services and infrastructure on both sides of the town’s main street but no pedestrian crossing which

meant residents with diminished mobility were being locked out of participation in their town because they could not cross the main street without risking their lives. One resident, a mature age woman with the late effects of polio, commenced an advocacy campaign for a crossing. She appealed to the Local government, the Business Association and State Department of Main Roads. There was much talk but all were reticent to act. Her State Post Polio organisation supported her to lodge a complaint to the Anti Discrimination Commission on the basis she was capable of being a customer yet being denied access to goods and services. It was her against a State Government Department afraid of setting a precedent for other towns on Highway 1. She supported her argument with data about the numbers of cohorts impacted: the over 60s, people with a medical condition, temporary injury, disability and parents with prams. Suitably, the matter was conciliated free of charge with agreement to install a controlled pedestrian crossing, a button activated, time controlled crossing that would stop traffic to permit safe crossing of the main street by pedestrians as required. *Result:* Citizens got the services they needed and shopkeepers had increased sales. Win, Win. Through this and many other examples, we should be heartened by the fact that individual advocacy, i.e. the power of one, using strategy and being supported by polio networks, can lead to much systemic change for access and inclusion for people everywhere.

## FP14

### “CLOSING THE CIRCLE” DEVELOPING A PARTNERSHIP BETWEEN POLIO SURVIVORS AND ROTARY – THE AUSTRALIAN EXPERIENCE

*John Tierney, OAM, PhD, President and National Patron Polio Australia*

The link between Rotary and polio survivors started in the 1920s when Rotary in Australia established six of the seven state based “Crippled Children’s Associations.” Over the last 40 years Rotary International has done outstanding work on the eradication of polio from the world and has now almost achieved that goal. In 2013, the executive of Polio Australia met with the Australian Rotary Governor’s Institute in Canberra and our message about Australia’s polio survivors was that “We’re still here!” We spoke of the need to re-establish support from Rotary, now that this cruel disease has left polio survivors with the Late Effects of Polio (LEOp) in our senior years. Since that time, a number of polio survivors have spoken to many of their local Rotary clubs urging them to help “close the circle” by turning some of their attention to Australia’s polio survivors. The response at the club level has been excellent with many Rotary members being completely unaware of the LEOp condition and of its incidence amongst older Australians. Talks have included “tutorials” on how polio actually affects the body initially and how this then leads to the LEOp condition. This new information has been well received by Rotarians. Most of the clubs that we have addressed have then gone on to support our work financially. Now, after several years, donations from Rotary clubs have become a significant stream of funding for Polio Australia programs. More recently Polio Australia has started to forge Rotary links at the district level, in particular, with Rotary District 9685, which covers the region north of Sydney Harbor. Following a successful trial of a health professional’s workshop on the polio body in Melbourne in 2014, District 9685 agreed to fund and help develop ten workshops across their district between November 2015 and May 2016. The success of these various workshops that were attended by a variety of local health professionals, depended on the level of teamwork between the local Rotary members and the Polio Australia providers of the services. We hope to learn a lot from this pilot project and believe that it could be a template for other Rotary districts for delivering training to health professionals on the management of the LEOp condition. At a higher level of engagement, in early September 2016, I will be a keynote speaker at the Rotary International Zone 7B & 8 Institute in Sydney on The Late Effects of Polio. This zone covers Australia and New Zealand. In such a way we will continue to explore how we can continue to “close the circle” and develop an even stronger partnership between Rotary and Polio Australia, to meet the needs of polio survivors.

**POLIO STORIES (PS01–PS05)****PS01****POLIO ERADICATION UPDATE****Jenny Horton, Registered Nurse Consultant***Australia*

Polio Eradication Initiative. In 1988, when the Global Polio Eradication Initiative began, polio paralysed more than 1,000 children worldwide every day. Supported by the Polio Eradication Partners, national governments in all but 2 countries have been able to stop polio transmission and the global incidence of polio cases has been decreased by 99%. Tackling the last 1% of polio cases has proved difficult. Conflict, political instability, hard-to-reach populations, and poor infrastructure continue to pose challenges to eradicating the disease. Serving on the front lines of the program for 15 years, Jenny will share her experiences and provide an update of the eradication program.

**PS02****KENYA, MAU-MAU AND POLIO IN 1954****Catherine Sharp, Expert Witness Nurse Consultant***Australia*

When the Mau-Mau conflict was underway in Kenya in the 1950's polio became a major problem. Those were the days before vaccination and many children of British soldiers, who were fighting the Mau-Mau, contracted the disease. Ambulance drivers would not pick sick children up to take them to hospital because they were afraid of being attacked by the Mau-Mau who hid in bushes along the dirt roads. Some doctors bravely took children and mothers by car to hospital but the delays in diagnosis and treatment, often in an iron-lung, meant that not all children lived. Others needed intubation and ventilation, calipers and walking frames. Those children who did survive now face the possible late effects of polio, something not recognized by many health care professionals. There is a need for education of healthcare workers to help them to recognize those patients at risk of falling and with breathing and swallowing difficulties, whether or not they have any visible signs of the disease. This is my story, and these are my memories, of polio in 1954.

**PS03****POLIO MANAGEMENT IN LIFE STAGES****Sai Padma Bellana, Advocate and Social Activist, with Pragjanand Busi, Therapist, Global Ability in Disability***India*

Polio: My Tryst with Polio in Life Stages So Far...! Polio is a strange disease. The more you want to know about it, the more it eludes you like life. I am Sai Padma, a polio survivor with 80% disability. Polio was like a mother, which gives birth to many other diseases/conditions/weaknesses and limitations in a body. It has given me severe scoliosis, weak lungs, slow motor functions in upper body, low motor functions in hands, obesity and a life time of weakness and pain and half participation in life. I used to walk, first with heavy metal hip knee ankle foot orthosis (HKAFO) and then KAFO and experienced every moment my general and other health declining. 7 fractures, several tendon transplantations and one major spine surgery made me sit on a wheelchair in 1995. I was operated for my scoliosis in 1996. I was in a wheelchair since then. We may hear several stories of disability and courage. But, I wish to spread the word of miracle in dispelling PPS. I had an interaction with PPS when I started feeling so weak and out of sync with life. Mornings were lazy and I get tired fast. Severe infections, and breathlessness and limb weakness followed. My paper and presentation covers, my life journey of 20 years from 25 years to 45 years, how I have challenged Post-Polio and Scoliosis effect with some ancient and modern methods which include, acupuncture, yoga, Ayurveda and

systemic changes in lifestyle. Main breakthrough in my life is when I have made myself fit for Dynamic bracings and tried the highly customized carbon graphite calipers. Life's never been easy for many persons with polio including me, but polio can be used against it and the fatigue and other symptoms can be overcome with diet, lifestyle, therapeutic regimen and fun activities. It's we who are stopping us towards full and active participation of life, not PPS. My paper deals around my life experiences with polio. Tips and tricks that I adopted and power of positive thinking and also negating the effects of Post-Polio Syndrome, from a person who couldn't sit more than half hour, now I work full time in different projects and have a very active life. My paper also revolves around importance of having a partner in life, like any management, it takes two to tango. I wish to dwell upon the contribution of my husband, who is a yoga and alternative therapist. How he made me out of medication, which I am so used to whole of my life. Since last 7 years I am not using any medication. My paper will deal with simple techniques of dealing with polio and finally dream of walking effortlessly.

**PS04****JAPANESE NETWORK OF POLIO SURVIVORS - HISTORY, ACTIVITIES AND FUTURE VISIONS****Tae Shibata, Welfare Advisor, Japanese Network of Polio Survivors***Japan*

*History of JNT:* – Organisation commenced in 2000. – Originally, eight regional groups joined. One group started independent activity in 2008. Another group joined with a neighboring group in 2010. JNT is currently made up of six groups. – Approximately nine hundred post-polio members. 90% of the members are more than 55-years-old. Eight members contracted polio through the oral-vaccination.

*Activities of JNT:* – Let polio people and their family know about PPS (what it is; how to diagnose; how to treat; how to find appropriate doctor, rehabilitation doctor and welfare service). – Informing doctors (neurology, orthopedic surgery, rehabilitation and home doctors), welfare workers, government officials about PPS using social media. – Provision of website: [www.zenkoku-polio.com/](http://www.zenkoku-polio.com/). – Periodical newsletter: Three to four times a year. – Publications: 1. For Understanding Polio and Post-Polio Syndrome (2000). 2. Managing Post-Polio Syndrome (2004) - Translation of the book of Lauro S Halstead. 3. Living with Post-polio Syndrome (2013). – Four regional groups of JNP have periodical checking programmes for PPS member's physical and locomotive conditions by rehabilitation doctors, PTs and OTs. One to three times a year. Other two groups are planning to set up similar programme. – Prof. Kazuhiko Abe, President of JNT, is on the national promotions team of JDA (Japanese Disabled Peoples' Act), as the representative of disabled patients' groups, and advising and commenting how to improve discrimination and inequality of disabled peoples.

*Future Vision of JNT:* – Communicating with international PPS groups. – Increase notification of PPS to polio people who still don't know about it. – Advocate for technology specialists and companies to produce convenient and reasonably-priced walking-aids, scooters, electric wheelchairs, rehabilitation aids and equipment and robotics. – Advocate for society and media to make barrier-free environments: No steps or stairs, installation of elevators, escalators and sliding-doors. – Provide psychological supports for PPS members.

*Public health insurance and nursing care insurance in Japan:* All residents of Japan enroll in National Health Insurance and pay an insurance premium of up to 850,000 yen/year/family – approx. AUD \$9,700 - depending on total income. It covers 70% of the medical expenses, including drug fee, examination fee (blood, urine, X-ray), surgical operation fee, and hospital costs. Over 40-years-old residents are eligible for Municipal Nursing Care Insurance. Premium is up to 176,000 yen/year/person – approx. AUD \$2,020 - depending on

total income. It covers 80-90% of the expenses, including costs of nursing care services (day and night care in nursing home, home visiting care by nurse and helper).

### **PS05**

#### **LIVING WITH POLIO IN THREE CONTINENTS**

*Neena Bhandari, Foreign Correspondent*

*Australia*

I contracted polio in India soon after receiving the triple dose of the Sabin oral polio vaccine (OPV), a month short of my third birthday. Unlike in the developed world, children with polio continued to live at home with their families in India. While children of my age played, I spent my days at the hospital doing physiotherapy and hydrotherapy. I learnt to walk with a rigid steel calliper and heavy boots - one bigger than the other to compensate the shortening in one leg. Growing up with polio during the 1970s and 1980s in a developing country had its own set of challenges despite having access to the best medical treatment available at that time. I went on to become a career journalist, reporting on issues ranging from environment and development, human rights and gender, education and health to crime and law. It was not until we moved to the UK in the late 1990s that I became aware of the many polio support groups, such as the British Polio

Fellowship in London and Post-Polio Health International in St Louis (USA). It provided a platform to discuss the many anxieties and medical interventions that become necessary as one grows old with polio. My greatest joy was to be able to walk and do what I wanted without stares and glares from the people around. Chance brought us to Australia, a country where sport is akin to religion. People's reactions to my disability here have both shocked and surprised me. In recent years, the onset of the Post Polio Syndrome has exacerbated the challenges of daily life. Osteopaenia in the polio leg, weakness in the good leg and imbalance have resulted in falls and fractures. It has been very difficult to find a doctor, a physiotherapist and an orthotist at the same place, who understands polio and PPS. Over the years, I have adopted my own self management strategies to prolong independent living and cope with pain. Spacing daily activities, using proper callipers and mobility aids, regular hydrotherapy [access into the pool can be an issue in community pools], meditation, yoga, Ayurvedic treatment and massage all help. However, it would be good to have more evidence-based research on the role of alternative and complementary therapies in PPS. Many bylines and many callipers on, cure for polio remains a cherished dream. But 2016 and beyond do hold promise of scientific and technological advancements that will improve and aid mobility. I am hoping to get my first carbonfibre orthosis this year. This presentation will chart my journey of living with polio and PPS in India, the UK and Australia.



## POSTER PRESENTATIONS (PP01–PP08)

### PP01

#### INVESTIGATION OF MOOD DISORDERS IN POLIO SURVIVORS - A RETROSPECTIVE AUDIT OF PATIENTS

*Russel Anbiah, Physiotherapist  
Polio Services Victoria, Australia*

Polio Services Victoria (PSV) is a state-wide service offering a multidisciplinary assessment and referral pathway for polio survivors. In order to provide a more holistic assessment, a validated measure, the Depression Anxiety and Stress Scale (DASS21), has been included as part of routine care to measure emotional distress since 2013. In this audit, the primary aim was to determine the incidence of depressed mood and/or anxious mood in our patient population and factors that may be related to mood disorders. The secondary aim was to investigate whether the factors of age, gender and/or low English proficiency were related to depressed or anxious mood. Implementation of the DASS21 highlighted that 46% and 62% of polio survivors had scores indicative of depressive and anxious mood respectively. No significant relationships were established between age, gender, English proficiency and mood. Further research incorporating other variables such as employment status, past trauma, extent of disability, financial burden, quality of life and clinical symptoms experienced may shed more light on mood disorders for this complex patient group. Managing emotional needs for polio survivors is crucial to successful implementation of self-management models of care. From the results of this audit, our service plans to investigate the effectiveness of referral pathways to local service providers for management of mood disorders. It is anticipated that managing emotional needs within a clinical setting will assist in patient engagement leading to lifestyle changes, increased empowerment and better quality of care.

### PP02

#### FORCE: EFFICACY-SAFETY OF INTRAVENOUS IMMUNOGLOBULIN IN PPS

*Sandra Camprubi, Global Clinical Research Leader  
Grifols Bioscience Industrial Group, Spain*

**Background:** Currently there is no proven curative treatment for Post-Polio Syndrome (PPS). Studies of cytokine levels in cerebrospinal fluid suggested an inflammatory component in its pathogenesis. This observation provided the rationale for testing intravenous immunoglobulin (IVIG) in PPS. Furthermore, IVIG is a safe and effective first-line therapy for several autoimmune neurologic diseases. Previous studies provided some evidence of benefit from use of IVIG in PPS but their results should be interpreted according to methodological limitations. **Objective:** To carry out the largest randomized trial (FORCE) in testing the clinical effect of IVIG in PPS, with longest duration of exposure and the first to compare two active arms of IVIG. **Study design:** FORCE is a phase II/III multi-center, prospective, randomized, placebo-controlled, double-blind and parallel group clinical trial with an adaptive design (flexible group sequential design with adaptive dose selection). Details are provided in Table 1. **Arms Stage 1:** IVIG 1 g/kg every 4 weeks vs IVIG 2 g/kg every 4 weeks vs placebo. **Stage 2:** Selected dose of IVIG from Stage 1 vs placebo. Treatment duration 1 year. Primary endpoint Physical performance (Two-Minute Walking Distance) from baseline to the end of the treatment period. Secondary endpoints - Pain (Visual Analogue Scale of pain). - Health Related Quality of Life (SF-36 Physical Component Summary). - Endurance (Six-Minute Walking Distance). Sample size Stage 1: 126 subjects. Stage 2: 84 subjects. **Discussion:** FORCE will be the first prospective, randomized, controlled trial to assess two active doses of IVIG administered every four weeks for a treatment period of one year.

### PP03

#### THE EXPERIENCE OF AGEING FOR PEOPLE WITH PHYSICAL IMPAIRMENTS WITH PARTICULAR REFERENCE TO POLIO SURVIVORS

*Margaret Cooper, Social Worker  
Post Polio Victoria, Australia*

An increasing number of Australia's ageing population are ageing with long-term physical impairments. A 2012 study explored the life experiences of a group using a qualitative approach. In depth interviews were conducted with 10 Victorians, aged between 51 and 84 years, who had lived with polio related or other impairments for at least 40 years. An inductive thematic analysis was undertaken. A relationship was found between the adaptive strategies which participants developed, as they moved through life phases and impairment stages. The implications of the emergence of a cyclical process of adaptation across the life course and particularly in respect of ageing, delivery of aged care services and social workers in this sector are discussed.

### PP04

#### ENGAGING WITH THE BOUNDARIES OF A LIFE WITH POLIO

*Anita Ghai, Professor  
School of Human Studies, Ambedkar University, India*

The story of my life has been marked with polio since the age of two. In this narration I will underscore the issues of not only my personal experience, but also the political implications. Polio involves not just the physical limits that are connected with a body that tends not to function in a 'normal' way, but also constitutes the person's predicament about the sense of self. Like all children, in my mind, I rationalised that Nature does not give everyone everything in full. We must lose some to gain others. As I grew I realised that persons with polio are products of an ideology of normality where communication of messages of the non-disabled body is a constant in any society. As a result, a person with polio is constantly in a mental state of deferment, awaiting the day the body will be not just be mended but cured. Until then, the polio survivors tend to impersonate the abled-bodied. Cure from pain and suffering has been a major preoccupation of Indian society. The cultural and religious rendering of disability leads to an obsessive hope and search for cure. Across the fifty-three years of my life, I have negotiated with shamans, gurus, tantric priests, and faith healers, as well as miracle cures – all to ensure that I could become a 'normal' person. Disability records not only the pain and anguish of disabled lives but families and their disabled children both learn to resist the stigma of disability. Though accustomed to talking about my experience with polio, I struggled to speak about its effect on my body, family and future. I never wanted to be identified with it – I didn't want to be singled out for who I was because of my condition. Thus, the comprehension and meaning of polio had to be negotiated as embedded in multiple cultural discourses with subtle nuances. Coming to terms with the conflicting social imagery about polio and the reality of my condition has been a long and lonely journey. I will exhibit polio's impact on body, family and future towards the end of 1980; I came into contact with the early understanding of the difference between impairment, disability and handicap and, finally, the disability rights movement. This helped me survive the overriding polio narrative of 'overcoming' and adopting the identity of the disability rights activist. However, my independence/dependence, in the physical world remains fluid. Enhancing the identity of polio, therefore, will remain complex. In a country like India, stigma, issues of gender, discrimination, access, and the state's attitude remain serious concerns. Rebuilding self-esteem and fragmented self are always on a continuum for a person with polio.

**PP05****THE INTERNATIONAL PREVALENCE OF POLIO: METHODOLOGY OF A SYSTEMATIC LITERATURE REVIEW****Kelly Jones, Senior Research Fellow***School of Public Health & Psychosocial Studies, AUT University, New Zealand*

**Introduction/Background:** While extensive resources have been devoted to preventing polio, recent accurate prevalence rates estimating the number of polio survivors at any given time are not available. It has been estimated that 12 to 20 million individuals are living with polio sequelae worldwide, yet current estimates are problematic. For example, definitions of "polio survivor" vary from including all those with a history of polio versus those with current symptoms and/or diagnosed with post-polio syndrome. Furthermore, regional prevalence figures are often crude and fragmented. Consequently, more accurate estimates of regional prevalence of polio survivors are required for efficient planning and appropriate resource allocation. **Methods:** Using established procedures for undertaking systematic reviews and search terms developed with Polio NZ Inc., a search of electronic academic databases and general internet searches will be conducted to include all recent studies published prior to December 2015. This electronic database search will be supported by contacting experts in the field and looking at reference lists of identified relevant articles to identify all literature exploring the prevalence of polio worldwide. The methodological quality of all identified studies will be reviewed using the STROBE guidelines for observational studies. **Outcomes:** Population based estimates of polio survivors will be derived from the international systematic literature review. Rates per 100,000 obtained from the literature review will be applied to the New Zealand population rate to ascertain an estimated prevalence rate. This will then be compared to existing prevalence data to obtain the most accurate prevalence rates of polio survivors in New Zealand to date. **Discussion:** A summary of relevant research identified during the systematic literature review will be presented. Any variations in study methodology, case ascertainment, target populations and verification procedures will also be discussed in terms of contributions to current prevalence estimates.

**PP06****GROWING OLDER WITH POST-POLIO SYNDROME: A NEEDS ASSESSMENT****Elizabeth Lounsbury, Chair, Post-Polio Canada**  
*Canada*

**Purpose:** The majority of polio survivors in North America are aged 60 and older, and evidence suggests that individuals with post-polio syndrome (PPS) experience aging differently than individuals who are aging into disability (rather than aging with a disability). For this reason, it is extremely important to understand the unique needs of this population and how their disability impacts their aging process. **Method:** Participants were recruited through March of Dimes Canada post-polio support groups. 10 adults over the age of 60 and diagnosed with PPS participated in individual phone interviews and four participated in a two-hour focus group. Participants were asked open-ended questions about their experience aging with PPS and to identify gaps in service delivery as they age with a physical disability. **Results:** A preliminary needs assessment conducted by the Department of Occupational Science and Occupational Therapy at the University of Toronto and March of Dimes Canada identified four major themes on the experience of aging with PPS: (1) maintaining independence is a priority; (2) social isolation is a consequence of PPS; (3) there is a lack of awareness of PPS among care professionals; and (4) navigation of services is difficult for people aging with PPS. **Conclusion:** Further research must be conducted to understand the needs of the aging with PPS population. The identification of the needs of the population will inform how social supports and services

developed primarily for the aging into disability population can be adapted to meet the needs of people aging with PPS, as well as those aging with other longstanding physical disabilities, to ensure continuity of care.

**PP07****INVESTIGATING COENZYME Q10 THERAPY FOR RELIEF OF THE FATIGUE OF THE LATE-ONSET SEQUELAE OF POLIOMYELITIS****Margaret Peel, Public Health Microbiologist (retired)**  
*Australia*

**Background:** Coenzyme Q10 has been shown to boost muscle energy metabolism in post-poliomyelitis subjects (1) but it does not promote muscle functioning in polio survivors with post-poliomyelitis syndrome (2). We aimed to assess, by a randomized placebo-controlled trial, whether the collective increased metabolic energy could alleviate the fatigue of the late-onset sequelae of poliomyelitis. **Methods:** Participants were recruited from the Post Polio Networks in Queensland and New South Wales which are support groups for polio survivors with diagnosed late-onset sequelae of poliomyelitis, including post-poliomyelitis syndrome. A moderate to high level of fatigue was required but those with fatigue-associated comorbidities of anaemia, diabetes, fibromyalgia and hypothyroidism were excluded. Also excluded were those being treated with warfarin or dabigatran (Pradaxa) which can interact with coenzyme Q10. On receipt of the consent forms, investigators phoned potential participants to confirm their eligibility. They were assigned (1:1), with stratification of the users of energy-saving motorized mobility devices, to receive 100 mg of coenzyme Q10 or placebo daily for 60 days. A novel colloidal formulation of coenzyme Q10 was used to enhance its enteral absorption and bioavailability. Participants and investigators were blinded to the group allocations. Fatigue was measured by the Multidimensional Assessment of Fatigue and the Fatigue Severity Scale since both are capable of detecting changes in fatigue after intervention (3). Scores for the latter are largely independent of the fatigue associated with depressive symptoms. Plasma coenzyme Q10 levels were measured to assess compliance. The trial was registered with the Australian New Zealand Trial Registry, number ACTRN 12612000552886. **Results:** Only 103 of the 535 invited were enrolled in the trial. Of these, 54 were assigned to receive coenzyme Q10 and 49 to receive placebo. The difference between the plasma levels of coenzyme Q10 for the two groups was highly significant confirming compliance. Adverse events were infrequent and unlikely to be attributable to coenzyme Q10 therapy. However, the difference in the mean score reduction in fatigue between the two groups was not statistically significant for either fatigue measure. **Conclusion:** A daily dose of 100 mg coenzyme Q10 for 60 days does not alleviate the fatigue of the late-onset sequelae of poliomyelitis.

**References**

1. Mizuno M, Quistorff B, Theorell H et al. *Molec Aspects Med* 1997; 18 Suppl: S291-8.
2. Skough K, Krossén C, Hiewe S et al. *J Rehabil Med* 2008; 40: 773-5.
3. Whitehead L. *J Pain Symptom Manage* 2009; 37: 107-28.

**PP08****POLIO AUSTRALIA'S RESEARCH DATABASE – A UNIQUE RESOURCE****Gillian Thomas, Vice-President, Polio Australia,**  
**President, Polio NSW**  
*Australia*

Polio Australia set up its Polio Health website (1) in 2015 as a dedicated resource for health professionals to learn about the diagnosis and management of the late effects of polio. The website includes sections about polio and its late effects, professional development opportunities, post-polio publications and videos, a health professionals register, post-polio conferences, the Australian Polio Register,

and post-polio research. This poster gives insights into the research database. The inspiration to set up a searchable database that focuses on post-polio research, and is readily accessible to all, came from Post-Polio Health International's Medical Articles (2) listing. Since the 1980s there has been considerable research into the causes and effects of, and diagnosis, treatment and therapies for, the late effects of polio and post-polio syndrome. Sadly, in Australia, there has been little interest or research in this area. The post-polio research database (3) seeks to bring relevant, credible, peer-reviewed, research papers to the attention of health professionals working with post-polio patients. In this endeavour, Polio Australia is grateful to Post-Polio Health International, Dr Mary Westbrook, and Dr Farid Khan, for their assistance in developing the database. There are currently around 200 research papers, including their abstracts, recorded in the database. The majority of the papers are available online, although a paid subscription may be required to view or download the full text. With research papers being added on an ongoing basis, the absence of any particular paper as at the database's last update is not a reflection on the value of that paper. The research is assembled under 44 categories: activity levels, acute flaccid paralysis, ageing, anaerobic threshold, anaesthesia, assistive technology, brain, cardiorespiratory, cardiovascular, clinical evaluation, cold intolerance, complementary

therapies, continence, coping styles and strategies, cultural context, diagnosis and management, differential diagnosis, drugs, dysphagia, dysphonia, epidemiology, exercise, falls, fatigue, fractures, gender differences, immune response, inflammation, late effects of polio, muscle strength, muscle atrophy, orthoses, pain, polio immunisation, post-polio motor unit, psychology, quality of life, renal complications, respiratory management, restless legs syndrome, sleep analysis, surgery, vitality, and vocational implications. For clinical trials, based on their results their efficacy is classified as effective, more research required, or not effective. For ease of locating papers of interest, they may be recorded in more than one relevant category. As well as being categorised, there is an alphabetical list of all papers, as well as lists sorted by author, category, journal, publication date, or title. The database is also fully searchable by author, category, journal, or title, or by any word within the abstracts. Finally, around 100 journals and other publications (to date) from which the research papers are drawn are listed separately in alphabetical order, each including a brief description. Each journal is linked to its website.

## References

1. [www.poliohealth.org.au](http://www.poliohealth.org.au)
2. [polioplacement.org/medical-articles](http://polioplacement.org/medical-articles)
3. [www.poliohealth.org.au/post-polio-research/](http://www.poliohealth.org.au/post-polio-research/)

## AUTHOR INDEX

**A**

Anbiah, Russel 742, 754

**B**

Badorrek, Bernard 739  
 Ball, Christine 745  
 Bellana, Sai Padma 752  
 Bertelsen, Merete 736, 744  
 Bhandari, Neena 753  
 Booy, Robert 738  
 Bringolf, Jane 748  
 Buchan, Ann 737  
 Busi, Pragjanand 752

**C**

Camprubi, Sandra 754  
 Chow, Yan 742  
 Cooper, Margaret 754

**D**

de Graaff, Stephen 736, 745  
 DeMayo, William 737, 745  
 Duncan, Anne 737, 746

**E**

Eulberg, Marny 735, 744

**G**

Ghai, Anita 754

**H**

Hartley, Anna 743  
 Headley, Joan 735, 740, 743  
 Heath, Nicola 750  
 Highley, Kerry 735, 748  
 Horton, Jenny 752

**J**

Jackman, Gordon 735, 750  
 Jegasothy, Gnanaletchumy 738  
 Jones, Kelly 755  
 Jupp, Tessa 746

**K**

Kay, Lise 736, 741, 744  
 Kennedy, Gayle 749  
 Knezevic, Danica 749

**L**

Lathlean, Tim 743  
 Layton, Natasha 743  
 Liethof, Mary-ann 735, 748

Loke, Marmaduke 738, 743

Lounsbury, Elizabeth 755

**M**

Machell, Stephanie 739, 746  
 Mackie, Helen 736, 744  
 Mayo, John 751  
 McClellan, Bruce (Mac) 747  
 McConaghy, Melissa 739  
 McFarlane, John R. 748  
 Morehouse, Catriona 742

**N**

Nielsen, Nete Munk 741  
 Nolan, Peter 738  
 Nollet, Frans 735, 747

**O**

Overall, Melinda 744

**P**

Peel, Margaret 755  
 Pereira, Darren 736  
 Petkoff, Margaret 742

**Q**

Quadros, Nigel 739, 745  
 Quinn, Frances 751

**R**

Roessler, Christa 743  
 Rope, Julie 750

**S**

Sharp, Catherine 750, 752  
 Shibata, Tae 752

**T**

Telford, Liz 749  
 Thomas, Gillian 749, 755  
 Tierney, John 751  
 Toniolo, Antonio 740

**V**

Vandenakker-Albanese, Carol  
 738, 746  
 Voorn, Eric 744