



STANDING COMMITTEE ON HEALTH AND AGEING

PO Box 6021, Parliament House, Canberra ACT 2600

Tel: (02) 6277 4145 | Fax: (02) 6277 4844 | Email: haa.reps@aph.gov.au | Web: www.aph.gov.au/haa

43rd Parliament

MEETING NO 52

Participant Papers

PUBLIC ROUNDTABLE: MELBOURNE

Roundtable on the
late effects of Polio/Post-Polio Syndrome

FRIDAY 30 MARCH 2012

10:00am–4:00pm

Committee Room G.9
Parliament of Victoria
55 St Andrews Place, East Melbourne Vic

Committee Secretary, Alison Clegg
Tel: (02) 6277 4157 (direct)
Email: alison.clegg.reps@aph.gov.au

Inquiry Secretary, Muzammil Ali
Tel: 02 6277 4590 (direct)
Email: muzammil.ali.reps@aph.gov.au

Interstate Mobile: 0421 053 822

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PROGRAM

PUBLIC ROUNDTABLE FORUM ON THE LATE EFFECTS OF POLIO/POST-POLIO SYNDROME (LEOP/PPS)

30 March 2012 – Melbourne
Committee Room G.9, Parliament of Victoria
55 St Andrews Place, East Melbourne Vic

TIME	ACTIVITY
10:00am	Welcome and introductions Each participant will have no more than 2 minutes to introduce themselves and/or the organisation that they are representing.
10:15am	Presentation Ms Gillian Thomas, President of Polio Australia will provide general background on the issue of LEOP/PPS.
10:45am	Topic 1: Definition, prevalence and diagnosis of LEOP/PPS <ul style="list-style-type: none">• Participant statements (Up to 5 mins)• Open discussion
12:00pm	<i>Lunch (provided for participants)</i>
1:00pm	Topic 2: Management of LEOP/PPS <ul style="list-style-type: none">• Participant statements (Up to 5 mins)• Open discussion
2:15pm	<i>Afternoon tea (provided for participants)</i>
2:30pm	Topic 3: Supports and services for LEOP/PPS <ul style="list-style-type: none">• Participant statements (Up to 5 mins)• Open discussion
3:45pm	Concluding remarks
4:00pm	<i>Close</i>

GUIDELINES FOR CONDUCT OF ROUNDTABLE

1. Participants

Due to space constraints, witnesses will be limited to those formally invited by the Committee. Participants are requested to arrive at least 15 minutes before the Chair's opening statement so that they can be seated by 10:00 am. The venue will be open from 9:30 am, with tea and coffee provided.

2. Time limits

To ensure that everybody has an equal opportunity to speak, the Chair will ensure that the specified time limits are strictly adhered to. During general discussion, the Chair may intervene if necessary to give all participants an opportunity to express their views. It is important that participants do not talk over each other as this makes it difficult for Hansard to record.

3. Opening statement at the start of proceedings

The Chair will make an initial opening statement.

4. Introduction of committee members and participants

The Chair will first invite members of the committee to introduce themselves. Although participants do not need to be sworn in, the Chair will then read a statement advising participants that the proceedings of the forum will be considered formal proceedings of Parliament. Following this statement the Chair will invite participants to state their name and the capacity in which they are attending the forum and make a brief introductory statement for no more than two minutes.

5. Roundtable themes

The remainder of the day's proceedings comprises interactive roundtable sessions to discuss key themes as outlined in this paper. The procedure for discussing the themes will follow a similar pattern. The Chair (or a member of the committee delegated by the Chair) will announce the theme and then invite each participant to speak to the theme for up to five minutes. Participants are advised that they are not obliged to make statement on a particular theme. For example, a participant may choose not to make a statement if they feel that an issue is outside their area of knowledge or that it has already been addressed by another participant.

Following the five minute statements, members of the committee will have the opportunity to ask questions before the Chair invites members and participants to engage in general discussion relevant to the theme. The general discussion will be the focal point of each session. It will allow clarification of issues and will provide the setting for participants to exchange ideas, and develop strategies and solutions to address issues.

6. Perspectives of participants

Participants at the table will have varying experiences and are well placed to comment on a range of issues. While individuals may be appearing in a particular capacity, this should not prevent them from drawing on the full extent of their experience in discussions.

7. Closing statements

Following discussion of the final topic, the Chair will invite each participant to make a final statement regarding the issues discussed at the roundtable forum. This is an opportunity for participants to leave the Committee with any final thoughts and perspectives which they may have. Statements should be for no more than two minutes.

8. Observers

Interested parties and members of the public will be able to attend the roundtable forum to observe proceedings. As observers, they will not be allowed to approach the table at any time during proceedings or to participate in the roundtable discussion.

9. Hansard/Broadcasting

The discussion will be recorded by Broadcasting. At the end of the day, the Chair will request a member to move that the proceedings of the forum be authorised for publication prior to formally closing the forum. A transcript of the discussions will be placed on the website and sent to all participants.

10. Discussion paper

Following the roundtable forum, the committee will prepare a discussion paper based on the proceedings of the day. All participants will receive a copy and the paper will be made available on the committee's website at:

http://www.aph.gov.au/Parliamentary_Business/Committees/House_of_Representatives_Committees?url=haa/leop%20pps/index.htm

MEMBERSHIP OF THE COMMITTEE

Chair Mr Steve Georganas MP
Member for Hindmarsh, SA (ALP)

Deputy Chair Mr Steve Irons MP
Member for Swan, WA (LP)

Members

Mr Mark Coulton MP
Member for Parkes, NSW (Nats)

Ms Jill Hall MP
Member for Shortland, NSW (ALP)

Ms Deborah O'Neill MP
Member for Robertson, NSW (ALP)

Mr Geoff Lyons MP
Member for Bass, Tas (ALP)

Mr Ken Wyatt MP
Member for Hasluck, WA (ALP)

PARTICIPANT'S BIOGRAPHICAL DETAILS

Mr Mark Booth

First Assistant Secretary, Primary and Ambulatory Care

Department of Health and Ageing

Mark Booth has a background as a health economist, working in health policy areas in the UK and New Zealand. He joined the Department of Health and Ageing in 2010, undertaking several Branch Head roles including responsibility for the development and implementation of the Medicare Locals initiative. Mark is First Assistant Secretary of the Primary and Ambulatory Care Division which aims to provide Australians with access to high quality, cost-effective, evidence-based primary care which coordinates with other types of care such as aged care services and hospital specialists.

Mark was a 2006–07 Commonwealth Fund Harkness Fellow in Health Care Policy.

Mr Blaise Doran

Physiotherapist and Coordinator

Polio Services Victoria

Blaise Doran qualified in the UK with a BSc (Hons) in Physiotherapy. The majority of his physiotherapy experience has been with people with neurological impairments and he has completed a Postgraduate Diploma in Neurological Rehabilitation from the University of Western Australia. Since February 2011, he has been employed by St Vincent's Hospital Melbourne as the coordinator and physiotherapist of Polio Services Victoria. It is a state-wide service, holding regular clinics in Melbourne and at six regional centres annually around the state. Mr Doran and his team see a small number of interstate patients.

With a team of four clinicians, their mandate is to provide:

- comprehensive assessment (treatment is provided to some individuals with complex presentations);
- case coordination through liaison with local service providers; and
- education and advice regarding polio and its late effects to patients, their loved ones, health care professionals and the wider community.

Dr Stephen de Graaff
Snr Rehabilitation Physician and Director of Pain Services
Epworth HealthCare

Dr. Stephen de Graaff is Director of Pain Services and Senior Rehabilitation Physician at Epworth HealthCare. He is a Fellow of the AFRM (RACP). His areas of research interest include Stroke Rehabilitation, Spasticity Management, Pain Management, Post-Polio Sequelae & Continuing Professional Development. He is currently Chairman of the Education Committee and in May 2012 will become President Elect of the Australasian Faculty of Rehabilitation Medicine (RACP).

Dr de Graaff has been managing and treating Polio Survivors for two decades. He has been involved in education of Polio Survivors and Health Professionals in the long term challenges facing the Polio Survivor.

Ms Mary-ann Liethof
National Program Manager
Polio Australia Inc

Mary-ann Liethof is the National Program Manager and only paid employee of Polio Australia Inc. She worked as Coordinator of Polio Network Victoria from 2004 to 2009, before being appointed by Polio Australia in January 2010 on a part time basis, which increased to full time in January 2011, following a 3 year philanthropic grant.

In 2008, Ms Liethof visited 10 post polio services in North America on a Churchill Fellowship, the purpose of which was *“To identify techniques to better manage the late effects of polio”*. In 2009, she attended Post-Polio Health International’s Wellness Retreat and Conference: *Living with Polio in the 21st Century* at Roosevelt Warm Springs, Georgia, USA. Using this experience, Ms Liethof ran Polio Australia’s first Wellness Retreat in 2010 in NSW, a second in Victoria in 2011, with a third scheduled for 2012 in Queensland. In 2011, Ms Liethof gave a presentation on this Program at the European Post Polio Conference in Copenhagen.

Ms Liz Telford
President
Post Polio Victoria Inc

Liz Telford contracted polio in 1956 at 6 months of age, in Melbourne and now experiences LEOP and PPS. Ms Telford is a qualified Accredited Mental Health Social Worker, and she has a Masters Degree in Family Therapy. She is President of Post Polio Victoria, an advocacy group established in 2010 which aims to raise awareness of the needs of people with post polio. In 2009 she attended the Polio Health International Conference in Warm Springs USA, and in 2011 attended the European Conference on Post Polio Syndrome in Copenhagen. From 2008 to 2010, Ms Telford was a member of the Polio Advisory Committee, which was linked to the information service provided by Independence Australia.

Ms Gillian Thomas
President (and polio survivor)
Polio Australia Inc

Gillian Thomas contracted paralytic polio at 10 months of age in 1950, 5 years before the first polio vaccine became available in Australia. Despite ongoing paralysis in 3 limbs, Gillian received a mainstream education and worked in managerial positions in both the government and community sectors. In 1996 the debilitating late effects of polio forced Gillian into early retirement.

In 1988 Gillian was a foundation member of Post-Polio Network (NSW), an organisation of which she is currently President. Gillian passionately believes in the need for a national voice for polio survivors and her efforts culminated in the highly successful meeting of all Australian State Polio Networks in May 2007 and the unanimous agreement to form Polio Australia. In 2008 Gillian was elected as Polio Australia's inaugural President and it is in this capacity that she is participating in the Roundtable Forum. Polio Australia is committed to standardising quality polio information and service provision across Australia for polio survivors.

Dr John Tierney, OAM
National Patron (and polio survivor)
Polio Australia Inc

In the 2012 Australia Day honours, Dr. John Tierney was awarded an Order of Australia Medal for services to education, the Parliament of Australia and the community.

John retired as a Partner at Government Relations Australia Advisory in 2011, following 14 years of distinguished service in the Australian Parliament, where he served as Senator for NSW until 2005. Prior to entering Parliament he was a senior lecturer at the University of Newcastle until 1991.

Additionally John has undertaken government relations advisory work on a pro bono basis for Lifeline Australia, Polio Australia and the Australian Association for the Education of the Gifted and Talented. He also currently sits on the Board of GERRIC (gifted education) at UNSW.

During his time in Parliament, Dr. Tierney was a Shadow Parliamentary Secretary to the Deputy Leader in the Senate and a Shadow Parliamentary Secretary for Communications, Information Technology and the Arts. John also chaired a number of Senate Standing and Select Committees over a range of portfolio areas, with a particular focus on Education, Employment, Industrial Relations, Communications/ICT, Transport, Health and Welfare issues.

Earlier in 2005, John co-sponsored the first National Parliamentary Inquiry into Mental Health. He has taken a passionate interest in the area of disability, having contracted polio at birth. John was a special parliamentary adviser to the Minister for Community Services on disability matters from 1999 to 2001.

Dr. Tierney was appointed to the Council of the Australian National University from 1996 to 2000 and to the Council of the National Library of Australia from 1992 to 2005. He has led Australian parliamentary delegations to South Africa (2002), Nigeria (2002), the European Union (2004), and to the United Nations in New York, where John led the Australian Parliamentary Delegation to the United Nations General Assembly in New York from September to December, 2004.

Prior to entering Parliament, Dr. Tierney was a Senior Lecturer in Education at the University of Newcastle until 1991 and Chairman of St. Philips Christian College where he is still Patron.

John holds the degrees of Doctor of Philosophy (Education) and Master of Education and Bachelor of Economics (University of Sydney and University of Newcastle).

BACKGROUND

Poliomyelitis, commonly referred to as 'polio', is a highly infectious viral disease for which there is no cure but for which effective vaccinations exist. Although polio was widespread in the Western world up until the early 1960s, international efforts to eradicate the disease have largely been successful.¹ In 2012, only three countries (Afghanistan, Nigeria and Pakistan) remain polio-endemic, down from more than 125 countries in 1988.²

Most people infected with polio have no symptoms or very mild symptoms.³ However, 1 in 200 infections leads to irreversible paralysis (usually in the legs) amongst those paralysed, 5% to 10% die when their breathing muscles become immobilized.⁴ Estimates indicate that up to 40,000 people were diagnosed with paralytic polio in Australia between 1930 and 1988.⁵

It has been noted that a large number of polio survivors will develop new, previously unrecognised symptoms years after their recovery from the acute disease.⁶ These new symptoms are commonly referred to as the late effects of polio (LEOP). Whilst LEOP refers to the full range of symptoms that individuals with a history of polio may experience, the medical community also identifies a specific diagnosable condition known as Post Polio Syndrome (PPS) that exists as a subset of LEOP.

The symptoms experienced by people with LEOP/PPS vary considerably in their range and severity but include:

- unaccustomed fatigue unrelated to activity;
- decreased strength and endurance;
- pain in muscles and/or joints;

¹ Global Polio Eradication Initiative (GPEI), Polio and Prevention website, <<http://www.polioeradication.org/Polioandprevention.aspx>>.

² World Health Organisation, Poliomyelitis website, <<http://www.who.int/mediacentre/factsheets/fs114/en/index.html>>.

³ GPEI, Polio and Prevention website, <http://www.polioeradication.org/Polioandprevention.aspx>.

⁴ Polio Australia, What is Polio? website, <http://www.polioaustralia.org.au/?page_id=33>.

⁵ Polio Australia, What are the late effects of polio? Website, <http://www.polioaustralia.org.au/?page_id=35>.

⁶ Polio Australia, Living with the late effects of polio. Website <<http://www.polioaustralia.org.au/>>

- an inability to stay alert;
- weakness and muscle atrophy;
- muscle and joint pain;
- muscle spasms/twitching;
- respiratory and sleep problems;
- swallowing or speaking difficulties; and
- a decline in the ability to perform basic daily activities.⁷

⁷ Polio Australia, What are the late effects of polio? Website, <http://www.polioaustralia.org.au/?page_id=35>.

PURPOSE FOR ROUNDTABLE FORUM

This roundtable is intended both to assist members of the Committee to gain a greater awareness of the issues surrounding LEOP/PPS. It also gives those in the LEOP/PPS community an opportunity to highlight issues and to put forward their views.

To promote broad, wide ranging discussion, three themes with a wide scope are proposed.

These topics are:

1. the definition, prevalence and diagnosis of LEOP/PPS;
2. the management of LEOP/PPS as a condition; and
3. support and services for those diagnosed with LEOP/PPS.

The topics and talking points proposed for discussion are illustrative of those that may arise, however the list is not intended to be exhaustive. Participants are advised that there is nothing to preclude consideration of relevant issues that have not been listed.

Prior to the commencement of the roundtable, each participant should familiarise themselves with the Guidelines for Conduct of Roundtable.

TOPIC 1: DEFINITION, PREVALENCE AND DIAGNOSIS OF LEOP/PPS

Session Background

Some literature and groups suggest that there are a range of inherent difficulties in the diagnosis of LEOP/PPS.¹ This session aims to discuss why these difficulties exist, how a diagnosis is currently made and what research is being conducted to increase the accuracy of diagnosis.

Possible talking points

- Post Polio Syndrome and the Late Effects of Polio – what is the difference?
- What research is conducted both domestically and internationally into LEOP/PPS?
 - How is this research shared?
 - How is this research improved?
- What research exists in terms of developing specific testing for LEOP/PPS?
- Anecdotally, it has been noted that misdiagnosis for LEOP/PPS is a common occurrence:
 - Why is this common?
 - What alternative diagnoses are made in lieu of LEOP/PPS?
 - What information/education could be provided to clinicians that would enable them to make a more accurate diagnosis? Who could provide this information?
 - Are there any tools which are used by clinicians in making a diagnosis?
- What is known regarding the prevalence of LEOP/PPS:
 - In Australia?
 - In other developed nations?
- Given difficulties with diagnosis of LEOP/PPS, how accurate is prevalence information?
- What are the impacts of LEOP/PPS on the quality of life of sufferers and carers?

¹ National Institute of Neurological Disorders and Stroke (NINDS), Post-polio syndrome fact sheet, <http://www.ninds.nih.gov/disorders/post_polio/detail_post_polio.htm> viewed 15 March 2012.

TOPIC 2: THE MANAGEMENT OF LEOP/PPS

Session background

This session aims to discuss how LEOP/PPS is managed including what techniques, therapies and aids exist for those diagnosed with LEOP/PPS. Also to be discussed is how clinicians and allied health professionals are trained and educated about current treatment techniques and therapies.

Possible talking points

- What does the current literature say about the management of LEOP/PPS?
- What are the most effective strategies that are suggested for the management of people with LEOP/PPS?
- How are clinicians and allied health professionals educated or trained about the best treatment for those with LEOP/PPS?
 - Who conducts this education or training?
 - How often is this training conducted or refreshed?
 - What sources of information do allied health professionals consult when seeking treatment options?
- What consultation occurs with the manufacturers of aids to assist people with LEOP/PPS?
- Is there consultation with the pharmaceutical industry in terms of research being conducted?

TOPIC 3: SUPPORTS AND SERVICES FOR LEOP/PPS

Session background

Providing adequate supporting those with LEOP/PPS is vital to survivors' quality of life.

Assistance currently comes in a variety of forms including from the non-government sector from organisations such as Polio Australia and other state and territory organisations. These organisations aim to provide information, and run conferences to help survivors and specialists working in the field of LEOP/PPS in order to increase awareness of the condition.

Possible talking points

- How are carers, family and friends educated or trained about the best treatment for people with with LEOP/PPS?
 - Who conducts this education or training?
 - How often is this training conducted or refreshed?
 - What sources of information do carers, family and friends use when seeking ways to provide support?
- What support and services exist from:
 - The Commonwealth Government?
 - State and Territory Governments?
 - Private and volunteer organisations?
- What structures exist within the Commonwealth Department of Health and Ageing to assist those with LEOP/PPS?
- What are the financial imposts upon those with LEOP/PPS?
 - What support is available in this regard?
- How are clinicians and allied health professionals provided with up to date information on sources of assistance and organisations who accept referrals for assistance?
- What coordination exists between Polio Australia and other state and territory bodies (such as post-polio networks)?
- Comment on the websites and web-based resources developed in both Queensland and Victorian Health Departments?
 - Are participants aware of other websites or web based resources?

- Are these websites adequate in terms of the information and resources that they provide?