The Parliament of the Commonwealth of Australia

Living with the pain of adhesive arachnoiditis

Report on the roundtable into adhesive arachnoiditis

House of Representatives
Standing Committee on Health and Ageing

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Canberra

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Foreword

There is no doubting the debilitating effects of chronic and severe pain. Sufferers of adhesive arachnoiditis and their families know this first hand. The impact on quality of life can be catastrophic, extracting a physical, social and emotional toll, not only on the person but also on his or her family.

That adhesive arachnoiditis is a little known condition, even among health professionals, means getting a diagnosis can be a lengthy and frustrating ordeal. The stress of living with this painful condition, for which there is currently no cure, is increased for some who attribute their adhesive arachnoiditis to medical procedures that were in fact intended to relieve their suffering.

By holding the roundtable and presenting this report to the Parliament, the Committee aims to raise the profile of adhesive arachnoiditis, highlight the challenges facing sufferers and identify some practical means of assistance for this group.

On behalf of the Committee, I extend thanks to all of the roundtable participants.

Ms Jill Hall MP
Chair

Membership of the Committee

Chair	Mr Steve Georganas MP *(to 27/11/12)*	
	Ms Jill Hall MP *(from 27/11/12)*	
Deputy Chair	Mr Steve Irons MP	
Members	Mr Mark Coulton MP	Mr Geoff Lyons MP
	Ms Deborah O'Neill MP	Mr Ken Wyatt MP

Terms of reference

The House of Representatives Standing Committee on Health and Ageing has resolved to conduct an inquiry by roundtable into adhesive arachnoiditis. The Committee's inquiry will focus on the aetiology, diagnosis, treatment and prognosis of adhesive arachnoiditis.

List of recommendations

Recommendation 1

In the context of corporate social responsibility the Committee encourages GlaxoSmithKline to consider establishing a charitable foundation to assist sufferers of adhesive arachnoiditis.

The foundation could operate as a flexible means of assisting those affected by adhesive arachnoiditis. Priorities for support would need to be established in consultation with sufferers of adhesive arachnoiditis and their families, but could include activities to:

- raise awareness of the condition;
- support research into adhesive arachnoiditis;
- coordinate adhesive arachnoiditis support groups;
- make representations to government;
- establish and maintain an Australian case register; and
- provide top-up funding for home modifications or other practical assistance.

Recommendation 2

The Royal Australian College of General Practitioners and Medicare Locals provide general practitioners with educational and training opportunities aimed at raising awareness of the diagnosis, symptoms and treatment of chronic adhesive arachnoiditis. The Australian and New Zealand College of Anaesthetists advise pain units and its membership of the likely incidence of adhesive arachnoiditis in the community.

Recommendation 3

Medicare Locals, and other health providers, actively engage with local communities and health professionals to determine the needs of people living with adhesive arachnoiditis and chronic pain, to develop strategies to assist sufferers optimise management of chronic pain and achieve the best possible quality of life.

Recommendation 4

The Australian Government, through the Australian Research Council and National Health and Medical Research Council, support research projects in relation to adhesive arachnoiditis, in particular areas that can be leveraged to a wider patient base, such as chronic pain management, particularly neuropathic pain.