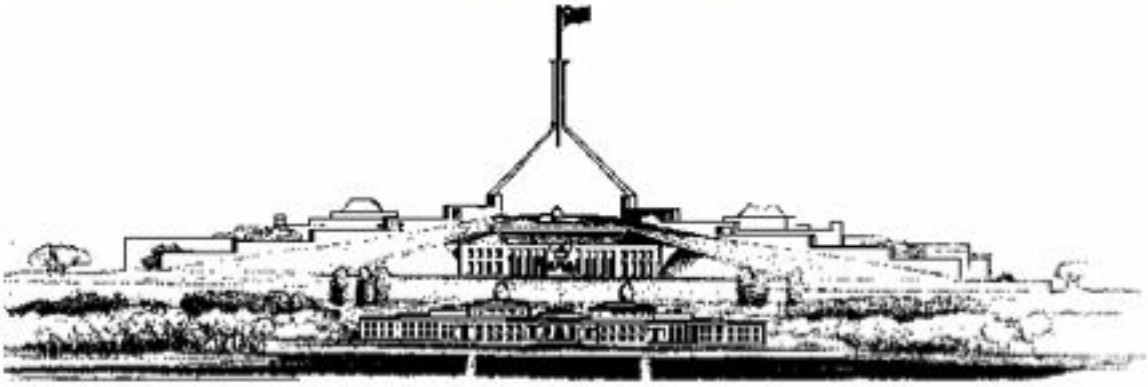
COMMONWEALTH OF AUSTRALIA

PARLIAMENTARY DEBATES



HOUSE OF REPRESENTATIVES

Main Committee

GRIEVANCE DEBATE

Adhesive Arachnoiditis

SPEECH

Monday, 19 September 2011

BY AUTHORITY OF THE HOUSE OF REPRESENTATIVES

SPEECH

Date	Monday, 19 September 2011	**Source**	House
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Questioner		**Responder**	
Speaker	Irons, Steve, MP	**Question No.**	

Mr IRONS (Swan) (21:00): I rise in this evening's grievance debate to speak about a situation where potentially thousands of Australians contracted the disease adhesive arachnoiditis after receiving a spinal injection of the chemical dyes Myodil or Pantopaque in the period from 1945 to the late 1980s. I bring to the attention of the House the sense of injustice and abandonment these people feel and to call for a parliamentary inquiry into their situation. At the outset, I would like to thank one of my Queens Park constituents, Mr Max Scott, a sufferer of adhesive arachnoiditis, for bringing this matter to my attention. Mr Scott attributes his contraction of arachnoiditis to his treatment with Myodil at Rivervale hospital in 1977. I would also like to thank the Parliamentary Library for the information that they have provided, which has been of great assistance as I have pursued information from Australian health authorities and as I prepared this speech.

Arachnoiditis is a debilitating neurological disease and, I think it would be fair to say, one of the most unpleasant diseases that one could suffer from. The condition itself is an inflammation of the arachnoid membrane. In many people, it affects the nerves running to the lower back and legs. The most common symptom is pain, but arachnoiditis can also cause (1) tingling, numbness or weakness in the legs; (2) sensations that may feel like insects crawling on the skin or water trickling down the leg; (3) severe shooting pain that can be similar to an electric shock sensation; (4) muscle cramps, spasms and uncontrollable twitching; and (5) bladder, bowel and/or sexual dysfunction. In its most severe form, this is an almost unbearable disease and, sadly, there are reports that many sufferers contemplate suicide. It slowly shuts the body down over a period of time.

When my constituent first raised this issue with me, he was able to walk into my East Victoria Park electorate office after driving himself from his home in Queens Park. Now, just a short time later, he is wheelchair bound and on the path to becoming a paraplegic. He suffers daily pain and there is little that can be done, as arachnoiditis is largely an incurable disease.

There are a variety of causes of arachnoiditis, one being the injection of a foreign substance, such as contrast media, into the spine. Unfortunately, the injection of the contrast media Pantopaque and Myodil, proprietary names of the chemical iophendylate, occurred widely in Australia between the 1940s and the 1980s. Iophendylate was injected into the spine and used as a radiological dye prior to the availability of MRI and CT technology. Once the dangers of the contrast medium and the link to adhesive arachnoiditis became apparent, the drug was withdrawn from the market across the world, but by then the damage had been done. Withdrawal did not occur at the same rate. There were reports that in Sweden it was banned in 1948, while in Australia it died a natural death in the eighties when MRI and CT scanning equipment became more widely used. Many questions have been raised as to how this contrast medium could have continued to be licensed for use in Australia up until the late 1980s.

This is a matter that has been raised in parliament before. Indeed, I acknowledge that this is not the first time that there have been calls for such an inquiry in this place. In 2002, the former member for Throsby, Jennie George, introduced a motion calling for an inquiry into this matter. Ms George referred evocatively to a 'conspiracy of silence about the incurable disease adhesive arachnoiditis', which she estimated to affect up to 60,000 Australian citizens. Ms George said questions needed to be answered about how a drug that had been introduced in Australia in 1945 and banned in Sweden in 1948 could have been used widely in Australia until withdrawn in 1987. I note that the current members for Boothby, Moore and Shortland also spoke on the motion. The member for Moore provided some details on the Commonwealth's role, stating:

Myodil was on the Australian market from at least 1959 and Pantopaque from at least 1961. Both agents were therefore available before the introduction of a therapeutic regulation program and requirements for premarketing evaluations in 1970.

The member for Shortland said that it was absolutely necessary that this is investigated. However, there was no subsequent inquiry, and the issue seems to have been put on the backburner ever since by governments of both persuasions.

An inquiry into this issue is long overdue, but now is an appropriate time. The slow decline in health for sufferers has meant that many people who were injected in the seventies and eighties are just beginning to suffer the ostensible effects of this disease today. It is in this context that Mr Scott approached me, asking for my assistance in getting to the bottom of this matter and seeing if there were any action he could take to achieve some assistance from the government.

I came to the chamber today to make this speech having made a great number of inquiries on his behalf to the Australian health establishment, and having received unsatisfactory results to date. I want to quickly brief the House on some of this correspondence now.

We wrote to the Minister for Health and Ageing on 27 July 2010, and this was responded to on 18 August by the head of the Office of Medicine Authorisation in the Therapeutic Goods Administration. In this reply we were referred to the Medical Board of Australia. Accordingly, I wrote to the Medical Board of Australia on Mr Scott's behalf on 7 September 2010. After some time without a response it was followed up by a personal letter from Mr Scott on 31 October 2010. The response of 10 November referred us on to the Office of Health Review. Accordingly, a third letter was written to Anne Donaldson, director of the Office of Health Review on 17 November 2010. She replied on 1 December, stating, 'Whilst I sympathise with Mr Scott's situation, this office is unable to assist him on this occasion. This is because our legislation prescribes that we should not deal with a complaint that is older than 24 months. While there is some discretion available, we are unable to deal with a complaint about matters that occurred prior to 1995.'

This handballing from one organisation to another suggests that either these organisations are unaware of their functions or that this is an issue that they just do not want to deal with. I suspect there may be a bit of both going on.

Given these unsatisfactory responses, I thought the appropriate course of action to take was to contact the Commonwealth Ombudsman, which I did on 13 January this year. However, to this day I still have not received an official written reply from the Ombudsman and nor has Mr Scott.

I am beginning to understand why the member for Throsby in 2002 spoke about a conspiracy of silence. It is this lack of interest and communication that has been an unending source of frustration for those affected by the disease, and it is why I call today on the parliament for an inquiry into this matter. The lack of interest from the Commonwealth Ombudsman is particularly disappointing, given the positive role played by the UK ombudsman in extracting information from Glaxo. According to the Parliamentary Library, an article written by Judy Jones in the *British Medical Journal* said that a member of the public complained to the ombudsman in 1998 after the UK Medicines Control Agency refused to disclose information about the safety, quality and efficacy of Myodil that had been considered in reaching the decision about the product licence in 1987. After the ombudsman's intervention the agency agreed to disclose a substantial amount of the information about Myodil.

As I have mentioned already, it is not just Australia where people were injected with this contrast medium. It happened across the world and, as such, it is worth considering what has happened overseas. In the UK Pantopaque was marketed as Myodil and was withdrawn from the market by its manufacturer, Glaxo, in 1987. According to research undertaken by the Parliamentary Library, Glaxo paid out £11 million in 1995 to 425 claimants in the UK, USA and Australia without accepting liability. The terms of the Glaxo payout were confidential, and there seems to be no information on how compensation has worked or was judged. The case that Glaxo regularly mounts in its defence is that by definition, people who had myelograms were already back sufferers.

In the US, where the substance was marketed under the Pantopaque name, the company was successfully sued by one person, but the settlement took place out of court. In New Zealand, the Accident Compensation Corporation made payments to a number of sufferers of iatrogenic arachnoiditis. Payments varied from person to person and, again, the details of the exact payments, the persons to whom they were made and the nature of the evidence available were not in the public domain.

Many support groups around the world have made allegations of an alleged conspiracy by manufacturers to continue to promote the use of the agent and compliance by medical staff in maintaining the use of the contrast

mediums Myodil and Pantopaque, despite the knowledge of a link with arachnoiditis. I understand that drug companies have settled many legal claims in the US, the UK and Australia out of court and on an individual basis, and that lawyers have deemed class action not to be viable.

The best committee to look into this matter is the House of Representatives Standing Committee on Health and Ageing, of which I am the deputy chair. Fortunately, the chair is in the chair here tonight. I requested of the committee chair that the committee initiate such an inquiry, and spoke in favour of it meeting in March. The committee has agreed to reconsider this as its next major inquiry, and I look forward to this happening.

In conclusion, it does seem that, whatever avenue one pursues, there is always a brick wall in the way. Even the Parliamentary Library has reported to my office that it is finding it difficult to get answers to some of its questions. The Prime Minister often talks about tearing down brick walls, and this is an ideal opportunity to do just that. It is time for an inquiry, and I thank you for your time because I have run out of time.