

**Senator Allison (Victoria) asked the Minister for Health and Ageing, upon notice, on 27 May 2003:**

**QUESTIONS ON NOTICE**

**Health: Human Pituitary Derived Hormone Treatment**

**Monday, 11 August 2003 Page: 13118**

<http://parlinfo.aph.gov.au/parlInfo/search/display/display.w3p;page=2;query=cjd%20hgh;rec=5;resCount=Default>

(1) Is the Minister aware that Professor Allars, on page 703 of the 1994 Allars Report, and the 1997 Community Affairs References Committee Report CJD» Settlement Offer stated that many recipients of pituitary-derived hormones experienced difficulties in accessing their medical files, stating that records were 'missing or destroyed'.

(2) Is the Minister aware that an 'unapproved' patient, who declared himself as a patient of Human Pituitary Advisory Committee (HPAC) doctors, could only obtain access to his medical files by applying to the Victorian Civil and Administrative Appeals Tribunal?

(3) (a) what does the department consider as an 'unapproved patient'; and (b) is it true that some 500 to 600 people fit this description.

(4) How can 'unapproved patients' prove themselves, given they often do not have access to their medical records unless they go through the courts, and nor are they able to access services provided to 'official recipients'.

(5) (a) Has the Minister been advised of this unfair treatment as stated in both reports; and (b) what does the Minister intend to do to redress this situation.

(6) Why has the department elected not to advise an 'unapproved recipient' of his hGH intravenous administration during the 'provocation' tests in which his treating hospital advised the department back in 1998.

(7) Will the Minister follow up on the 'unapproved recipients' who were declared to the department and who the Department elected not to advise of their treatment.

(8) Can the Minister explain why it takes 10 years for an 'unofficial recipient' to discover his medical treatment under the HPAC.

(9) (a) Can the Minister explain why some hGH batches were excluded from the information tabled in the Allars Report, namely hGH70, hGH102, hGH104 and hGH105; and (b) given the department holds a document on this 'unapproved recipient' dated 1978, after being disclosed as a recipient, why did the department elect not to advise this recipient of his treatment 20 years later in 1998 when his hospital contacted the department.

(10) (a) Can the Minister explain why this patient was written to by both the department and his treating endocrinologist stating that he was never treated with pituitary-derived hormones, when this now proves to be incorrect.

(11) (a) How could this mistake have been made; and (b) what structures are in place to ensure that it does not happen again.

(12) Given the release of this recipient's medical files under the Freedom of Information Act, and the release of his 'provocation tests' and results, what is the Minister doing about those who were 'Steroid Primed' and chemically castrated as a result of the program.

(13) In light of this new information and the clinical investigation undertaken prior to any 'growth treatment', showing that this 'unapproved recipient' was a healthy child, showing no endocrine abnormalities with normal growth hormone levels: why was the child experimented on.

(14) Why does the department refuse to follow up on these subjects who were merely short for their age with no growth dysfunction, who ended up being treated with toxic drugs, namely anabolic steroids.

(15) Does the Minister agree that both the Senate inquiry and the 'unapproved recipients' of this program have been misled about this treatment?

**Senator Patterson (Victoria) (Minister for Health and Ageing) —the answer to the honourable senator's question is as follows:**

(1) I am aware that on page 637 it is reported that many of the records were destroyed with the retirement or death of the treating medical practitioners.

(2) No.

(3) (a) The Department considers an 'unapproved patient' as a patient who received treatment without the approval from the Human Pituitary Advisory Committee (HPAC).

(b) No. There are 125 people known to have been treated outside the Australian Human Pituitary Hormone Program (AHPHP). One hundred and two of these people have been traced.

(4) Any individual who believes that they have received or been treated with human pituitary derived hormones should contact the Department of Health and Ageing by calling the free call number 1800 802 306. Procedures have been developed in order to verify such claims.

(5) (a) No.

(b) See (4) above.

(6) I am not aware of any recipient whom the Department has been able to trace, not receiving all their relevant information from the Department if they requested it.

(7) The Department has not elected not to advise 'unapproved recipients' of their treatment. As of April 2000 a total of 93.7% of all people treated with pituitary derived hormones had been traced by the Department. All methods of tracing have been now exhausted. The Department received Ministerial approval to cease tracing efforts from the then Minister of the Department of Health and Ageing, Dr Wooldridge in May 2000.

(8) No. See (7) above.

(9) (a) No.

(b) See (6) above.

(10) The Department has no evidence of this correspondence - see (6) above.

(11) (a) and (b) See (6) above.

(12) Steroid priming was not a requirement under the Guidelines for approval for «hGH therapy. This treatment is not related to the AHPHP.

(13) This question should be directed to the treating physician.

(14) This treatment was not related to the AHPHP. The reasons for decisions made by individual treating practitioners should be sought from the practitioners.

(15) No.