



Australian Government
Repatriation Medical Authority

EXPLANATORY STATEMENT

**STATEMENT OF PRINCIPLES CONCERNING
PORPHYRIA CUTANEA TARDA
(BALANCE OF PROBABILITIES) (NO. 70 OF 2021)**

***VETERANS' ENTITLEMENTS ACT 1986
MILITARY REHABILITATION AND COMPENSATION ACT 2004***

1. This is the Explanatory Statement to the *Statement of Principles concerning porphyria cutanea tarda (Balance of Probabilities)* (No. 70 of 2021).

Background

2. The Repatriation Medical Authority (the Authority), under subsection 196B(8) of the *Veterans' Entitlements Act 1986* (the VEA), repeals Instrument No. 44 of 2012 (Federal Register of Legislation No. F2012L01358) determined under subsection 196B(3) of the VEA concerning **porphyria cutanea tarda**.
3. The Authority is of the view that on the sound medical-scientific evidence available it is more probable than not that **porphyria cutanea tarda** and **death from porphyria cutanea tarda** can be related to particular kinds of service. The Authority has therefore determined pursuant to subsection 196B(3) of the VEA a Statement of Principles concerning **porphyria cutanea tarda** (Balance of Probabilities) (No. 70 of 2021). This Instrument will in effect replace the repealed Statement of Principles.

Purpose and Operation

4. The Statement of Principles will be applied in determining claims under the VEA and the *Military Rehabilitation and Compensation Act 2004* (the MRCA).
5. The Statement of Principles sets out the factors that must exist, and which of those factors must be related to the following kinds of service rendered by a person:
 - eligible war service (other than operational service) under the VEA;
 - defence service (other than hazardous service and British nuclear test defence service) under the VEA;
 - peacetime service under the MRCA,

before it can be said that, on the balance of probabilities, porphyria cutanea tarda or death from porphyria cutanea tarda is connected with the circumstances of that service. The Statement of Principles has been determined for the purposes of both the VEA and the MRCA.

6. This Instrument results from an investigation notified by the Authority in the Government Notices Gazette of 29 October 2019 concerning porphyria cutanea tarda in accordance with section 196G of the VEA. The investigation involved an examination of the sound medical-scientific evidence now available to the Authority, including the sound medical-scientific evidence it has previously considered.

7. The contents of this Instrument are in similar terms as the repealed Instrument. Comparing this Instrument and the repealed Instrument, the differences include:
- adopting the latest revised Instrument format, which commenced in 2015;
 - specifying a day of commencement for the Instrument in section 2;
 - revising the definition of 'porphyria cutanea tarda' in subsection 7(2);
 - revising the reference to 'ICD-10-AM code' in subsection 7(4);
 - revising the factors in subsections 9(1) and 9(11) concerning consuming alcohol, for males;
 - revising the factors in subsections 9(2) and 9(12) concerning consuming alcohol, for females;
 - new factors in subsections 9(3) and 9(13) concerning having alcohol use disorder;
 - new factors in subsections 9(4) and 9(14) concerning having cirrhosis of the liver or steatohepatitis;
 - new factors in subsections 9(5) and 9(15) concerning having chronic renal failure;
 - revising the factors in subsections 9(6) and 9(16) concerning having hepatic iron overload, by the inclusion of a note;
 - new factors in subsections 9(7) and 9(17) concerning having a viral infection from the specified list of viral infections;
 - revising the factors in subsections 9(8) and 9(18) concerning taking a drug from the specified list of drugs;
 - revising the factors in subsections 9(9) and 9(19) concerning taking a drug;
 - new factor in subsections 9(10) and 9(20) concerning ingesting food contaminated with hexachlorobenzene;
 - deleting the factors concerning having a liver disease from the specified list, as these are now covered by the factors in:
 - subsections 9(4) and 9(14) concerning having cirrhosis of the liver or steatohepatitis; and
 - subsections 9(7) and 9(17) concerning having a viral infection from the specified list of viral infections;
 - deleting the factors concerning undergoing haemodialysis or peritoneal dialysis, as these are now covered by the factors in subsections 9(5) and 9(15) concerning having chronic renal failure;
 - deleting the factors concerning being infected with human immunodeficiency virus, as these are now covered by the factors in subsections 9(7) and 9(17) concerning having a viral infection from the specified list of viral infections;
 - deleting the factors concerning taking a course of oral oestrogen therapy, as these are now covered by the factors in subsections 9(8) and 9(18) concerning taking a drug from the specified list of drugs;
 - deleting the factors concerning having exposure to a halogenated aromatic hydrocarbon as specified, as these are now partially covered by the factors in subsections 9(10) and 9(20) concerning ingesting food contaminated with hexachlorobenzene;
 - deleting the factors concerning having the affected area of skin exposed to sunlight or ultraviolet light;
 - deleting the factors concerning having a porphyrin-generating hepatocellular tumour;

- deleting the factors concerning having exposure as specified to a chemical agent contaminated with 2,3,7,8-tetrachlorodibenzo-para-dioxin (TCDD);
- new definitions of 'chronic renal failure', 'MRCA', 'specified list of drugs', 'specified list of viral infections' and 'VEA' in Schedule 1 - Dictionary;
- revising the definitions of 'iron overload' and 'relevant service' in Schedule 1 - Dictionary; and
- deleting the definitions of 'a drug or a drug from a class of drugs from the specified list', 'a halogenated aromatic hydrocarbon from the specified list', 'alcohol', 'a liver disease from the specified list', 'a specified chemical agent', 'having exposure as specified to a chemical agent contaminated with 2,3,7,8-tetrachlorodibenzo-para-dioxin (TCDD)', 'having exposure to a halogenated aromatic hydrocarbon' and 'porphyrin-generating hepatocellular tumour'.

Consultation

8. Prior to determining this Instrument, the Authority advertised its intention to undertake an investigation in relation to porphyria cutanea tarda in the Government Notices Gazette of 29 October 2019, and circulated a copy of the notice of intention to investigate to a wide range of organisations representing veterans, service personnel and their dependants. The Authority invited submissions from the Repatriation Commission, the Military Rehabilitation and Compensation Commission, organisations and persons referred to in section 196E of the VEA, and any person having expertise in the field. No submissions were received for consideration by the Authority in relation to the investigation.
9. On 3 March 2021, the Authority wrote to organisations representing veterans, service personnel and their dependants regarding the proposed Instrument and the medical-scientific material considered by the Authority. This letter emphasised the deletion of factors relating to *having exposure as specified to a chemical agent contaminated with 2,3,7,8-tetrachlorodibenzo-para-dioxin (TCDD) within the one year before the clinical onset of porphyria cutanea tarda, having a porphyrin-generating hepatocellular tumour at the time of the clinical onset of porphyria cutanea tarda, having the affected area of skin exposed to sunlight or ultraviolet light within the five days before the clinical onset of porphyria cutanea tarda, having exposure as specified to a chemical agent contaminated with 2,3,7,8-tetrachlorodibenzo-para-dioxin (TCDD) within the one year before the clinical worsening of porphyria cutanea tarda, having a porphyrin-generating hepatocellular tumour at the time of the clinical worsening of porphyria cutanea tarda and having the affected area of skin exposed to sunlight or ultraviolet light within the five days before the clinical worsening of porphyria cutanea tarda.* The Authority provided an opportunity to the organisations to make representations in relation to the proposed Instrument prior to its determination. No submissions were received for consideration by the Authority. No changes were made to the proposed Instrument following this consultation process.

Human Rights

10. This instrument is compatible with the Human Rights and Freedoms recognised or declared in the International Instruments listed in Section 3 of the *Human Rights (Parliamentary Scrutiny) Act 2011*. A Statement of Compatibility with Human Rights follows.

Finalisation of Investigation

11. The determining of this Instrument finalises the investigation in relation to porphyria cutanea tarda as advertised in the Government Notices Gazette of 29 October 2019.

References

12. A list of references relating to the above condition is available on the Authority's website at: www.rma.gov.au. Any other document referred to in this Statement of Principles is available on request to the Repatriation Medical Authority at the following address:

Email: info@rma.gov.au

Post: The Registrar
Repatriation Medical Authority
GPO Box 1014
BRISBANE QLD 4001



Australian Government
Repatriation Medical Authority

Statement of Compatibility with Human Rights

(Prepared in accordance with Part 3 of the Human Rights (Parliamentary Scrutiny) Act 2011)

Instrument No.: **Statement of Principles No. 70 of 2021**

Kind of Injury, Disease or Death: **Porphyria cutanea tarda**

This Legislative Instrument is compatible with the human rights and freedoms recognised or declared in the international instruments listed in section 3 of the *Human Rights (Parliamentary Scrutiny) Act 2011*.

Overview of the Legislative Instrument

1. This Legislative Instrument is determined pursuant to subsection 196B(3) of the *Veterans' Entitlements Act 1986* (the VEA) for the purposes of the VEA and the *Military Rehabilitation and Compensation Act 2004* (the MRCA). Part XIA of the VEA requires the determination of these instruments outlining the factors connecting particular kinds of injury, disease or death with service such being determined solely on the available sound medical-scientific evidence.
2. This Legislative Instrument:-
 - facilitates claimants in making, and the Repatriation Commission and the Military Rehabilitation and Compensation Commission in assessing, claims under the VEA and the MRCA respectively, by specifying the circumstances in which medical treatment and compensation can be extended to eligible persons who have porphyria cutanea tarda;
 - facilitates the review of such decisions by the Veterans' Review Board and the Administrative Appeals Tribunal;
 - outlines the factors which the current sound medical-scientific evidence indicates must exist before it can be said that, on the balance of probabilities, porphyria cutanea tarda is connected with the circumstances of eligible service rendered by a person, as set out in clause 5 of the Explanatory Statement;
 - replaces Instrument No. 44 of 2012; and
 - reflects developments in the available sound medical-scientific evidence concerning porphyria cutanea tarda which have occurred since that earlier instrument was determined.
3. The Instrument is assessed as being a technical instrument which improves the medico-scientific quality of outcomes under the VEA and the MRCA.

Human Rights Implications

4. This Legislative Instrument does not derogate from any human rights. It promotes the human rights of veterans, current and former Defence Force members as well as other persons such as their dependents, including:
- the right to social security (Art 9, *International Covenant on Economic, Social and Cultural Rights*; Art 26, *Convention on the Rights of the Child* and Art 28, *Convention on the Rights of Persons with Disabilities*) by helping to ensure that the qualifying conditions for the benefit are 'reasonable, proportionate and transparent'¹;
 - the right to an adequate standard of living (Art 11, ICESCR; Art 27, CRC and Art 28, CRPD) by facilitating the assessment and determination of social security benefits;
 - the right to the enjoyment of the highest attainable standard of physical and mental health (Art 12, ICESCR and Art 25, CRPD), by facilitating the assessment and determination of compensation and benefits in relation to the treatment and rehabilitation of veterans and Defence Force members;
 - the rights of persons with disabilities by facilitating the determination of claims relating to treatment and rehabilitation (Art 26, CRPD); and
 - ensuring that those rights "will be exercised without discrimination of any kind as to race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status" (Art 2, ICESCR).

Conclusion

This Legislative Instrument is compatible with human rights as it does not derogate from and promotes a number of human rights.

Repatriation Medical Authority

¹ In General Comment No. 19 (The right to social security), the Committee on Economic, Social and Cultural Rights said (at paragraph 24) this to be one of the elements of ensuring accessibility to social security.