

**Media release**

Embargoed 5am Sunday, 2 March 2025

**PBS listing for new Cushing's Disease treatment welcomed – but it's only the beginning say patients**

Australians with pituitary disease and disorders have today welcomed a decision to list Osilodrostat (Isturisa) on the Pharmaceutical Benefits Scheme (PBS) from 1 March this year.

The decision offers hope to many Australians with Cushing's Disease, a debilitating condition with significant health impacts and very limited treatment options.

It is estimated up to 1600 Australians are living with Cushing's Disease, with about 41 new cases of the disease diagnosed across the country each year.

People with Cushing's Disease suffer from an over-production of the stress hormone cortisol which is often caused by a pituitary tumour or other hormone-producing tumour. It can have devastating physical and mental health consequences.

Chair of the Australian Pituitary Foundation (APF) Malini Raj said without access to Osilodrostat, many patients would be left with no alternative but to undergo adrenalectomy – a major, irreversible surgery to remove their adrenal glands that brings a whole new range of health challenges.

“Making Osilodrostat more accessible and affordable through the Pharmaceutical Benefits Scheme is a welcome step but more is needed to tackle pituitary disease and disorders”, Ms Raj, who has Cushing's Disease, said.

“At least 1 in 1,000 Australians will develop a pituitary disease or disorder in their lifetime. These are diseases and disorders in urgent need of a common funding commitment by all sides of politics in Australia.

“We're calling for a comprehensive pituitary healthcare funding package that guarantees patients access to earlier diagnosis, best quality care, cheaper medications, and research into cures and better treatments.”

Professor Ann McCormack, past president of the Endocrine Society of Australia and a member of the APF's Medical Advisory Committee, says that while Cushing's and other pituitary diseases did not have a high profile in Australia, it was important to know that they had the potential to be as deadly as cancer and other chronic diseases.

“As an endocrinologist who sees hundreds of pituitary patients, I know how devastating pituitary disease and disorders can be and how desperately we need funding for pituitary medicine and research, Professor McCormack said.



### **About the Pituitary Gland**

The pituitary gland is located at the base of the brain, roughly in line with the top of the nose. It is quite small (about the size of a pea). The pituitary is often called the “master gland”, as it controls the functioning of many other endocrine glands of the body, including the thyroid, adrenals and reproductive glands.

### **About the Australian Pituitary Foundation**

The Australian Pituitary Foundation was founded in Sydney in 1994 by pituitary patients and family members. The national not-for-profit organisation aims to improve quality of life for patients living with pituitary conditions and their families, through increasing awareness and providing valuable support and information.

For more information – visit the website - [www.pituitary.asn.au](http://www.pituitary.asn.au)

*Please contact APF Chair Malini Raj on 0403 028 438 for further media comment.*