



Special Commission of Inquiry into Healthcare Funding

Submission Number: 189
Name: Australian Pituitary Foundation
Date Received: 3/12/2023

Submission to the NSW Government's Special Commission of Inquiry into Healthcare Funding – Australian Pituitary Foundation

The Australian Pituitary Foundation welcomes the NSW Government's Special Commission of Inquiry into Healthcare Funding.

We welcome this opportunity to:

- improve healthcare services for the 1 in 1000 NSW residents who are likely to be diagnosed with a pituitary tumour
- ensure NSW residents who are diagnosed with a pituitary tumour receive high quality, timely, equitable and accessible patient-centred care
- increase engagement and involvement of communities in health service development and delivery.

About the Australian Pituitary Foundation

The Australian Pituitary Foundation is a national not-for-profit organisation founded in Sydney in 1994 by pituitary patients and family members.

Our vision is an improved quality of life for patients living with pituitary conditions and their families.

Our mission is to increase awareness and provide valuable support and information for patients living with pituitary conditions and their families.

The Australian Pituitary Foundation does not currently receive any NSW Government funding and relies on limited donations and grants.

About pituitary tumours

Pituitary tumours are common but are substantially under-recognised and represent a serious unmet health care need in NSW and around Australia.

Around 1 in 1000 individuals have a clinically significant pituitary tumour.

Located at the base of the brain, pituitary tumours can have devastating effects a person's health, including vision impairment and loss, disruption of hormone regulation, interference with vital bodily functions, and greatly impact a person's quality of life.

The peak age at which people are diagnosed with a pituitary tumour is 40 years of age.

Current state of pituitary healthcare services in NSW

Early diagnosis, care from an endocrinologist with experience in managing pituitary diseases, and involvement from a neurosurgeon with pituitary expertise is considered essential for optimal patient outcomes.

However, low awareness of pituitary tumours and their symptoms among General Practitioners, other the healthcare professionals, and the broader community in NSW has contributed to delays in patients being diagnosed.

Once diagnosed with a pituitary tumour, patients in NSW also face difficulties navigating the NSW healthcare system and determining which doctors are the most qualified to treat pituitary tumours.

Put together, pituitary patients in NSW who experience delays to diagnosis and who are not treated by the most qualified doctors experience less than optimal outcomes and may require further surgeries and treatments.

The impacts also extend beyond physical, to emotional, financial, and social. This also places significant strain and pressure on the NSW healthcare system and productivity losses to society.

Proposed Solutions

The Australian Pituitary Foundation proposes four key strategic initiatives to assist the NSW Government in improving how health funding is effectively allocated to support the safe delivery of high quality, timely, equitable and accessible patient-centred care and health services to people in NSW diagnosed with pituitary tumours.

These strategic initiatives are also centred around the NSW Government's interest in engagement and involvement with communities in health service development and delivery.

Strategic Initiative #1: A comprehensive education and awareness raising campaign

By running a comprehensive education and awareness raising campaign, the NSW Government will improve awareness in the broader community and among underrepresented/minority groups in NSW leading to better patient outcomes.

It will also equip people in NSW with the questions to ask their doctors to help reduce the time it takes to be diagnosed.

Strategic Initiative #2: Dedicated Australian Pituitary Foundation Nurse Help Line

By providing this critical specific medical-related support for the community, the NSW Government can reduce pressure on the NSW healthcare system and reduce the number of pituitary patient admissions at NSW hospital emergency departments.

Strategic Initiative #3: Develop a General Practitioner Accreditation Program

The NSW Government has an opportunity to lead the nation by establishing a General Practitioner Accreditation Program for pituitary conditions.

Such a program would be aimed at increasing awareness of pituitary conditions among general practitioners and helping general practitioners to recognise pituitary conditions and symptoms early.

The contribution of general practitioners to early detection of pituitary tumours will increase the likelihood of optimal patient outcomes and reduce pressure on the NSW healthcare system.

Strategic Initiative #4: Ongoing Patient Advocate Support

The Australian Pituitary Foundation provides a vital service to pituitary patients and their families. We provide resources and connection. Our network of pituitary patient support volunteers (who have lived experience) helps pituitary patients to navigate the health system, find the care they need, and gain mental health benefits through connection with other pituitary patients.

By supporting the Australian Pituitary Foundation in this vital work providing information and support, the NSW Government will help pituitary patients experience better health outcomes while reducing pressure on the NSW health system.

We would welcome the opportunity to discuss any of the above further.

Contact

Malini Raj
Australian Pituitary Foundation Co-chair

