



## Special Commission of Inquiry into Healthcare Funding

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Commissioner Richard Beasley SC,

As Australia's leading expert on pituitary disease, I welcome the NSW Government's Special Commission of Inquiry into Healthcare Funding.

There is a serious unmet clinical need in resourcing for the management of pituitary disease. These are common and life-changing conditions.

Located at the base of the brain, the pituitary gland is responsible for the regulation of multiple hormone-producing organs in the body. Yet there is no dedicated funding to support pituitary patients and much needed research to better manage these conditions.

I welcome this opportunity to:

- improve healthcare services for NSW residents who suffer and who are likely to suffer from a pituitary condition sometime in the future. This includes the 1 in 1000 NSW residents who are likely to be diagnosed with the pituitary tumour, the 1 in every 3 patients with a traumatic brain injury who are living with pituitary deficiency, and the increasing numbers of cancer patients who are losing pituitary function as a side effect from receiving immune therapy
- ensure NSW residents who are diagnosed with a pituitary tumour or other pituitary condition receive high quality, timely, equitable and accessible patient-centred care
- advocate for proper funding to enable multi-disciplinary care that pituitary patients in NSW need to experience optimal health outcomes
- champion clinical innovations aimed at improving health outcomes for patients diagnosed with pituitary disease in NSW.

### **About my work**

**I lead Australia's only dedicated research group for pituitary tumours and pituitary conditions.**

Providing hope to people affected by pituitary conditions, my research group is based out of St Vincent's Hospital and the Garvan Institute of Medical Research in Sydney.

My research group is:

- focused on better detection and management of pituitary tumours, and
- pioneering genetic testing for pituitary tumours in the era of genomic sequencing to enable personalised treatments
- exploring the diagnosis and management of pituitary deficiency in the setting of traumatic brain injury.

In addition to the research I lead, as a practising specialist pituitary endocrinologist I **chair the St Vincent's Hospital Sydney Multidisciplinary Pituitary Team** which comprises members of endocrinology, neurosurgery, ENT, pathology, radiology, and oncology departments.

**My Multidisciplinary Pituitary Team is the most experienced in NSW, currently caring for more than two thirds of all pituitary patients in the State.**

Since 2012, my Multidisciplinary Pituitary Team has treated more than 1000 patients with pituitary tumours.

### **About pituitary tumours**

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

Around 1 in 1000 individuals have a clinically significant pituitary tumour. This is based on international data as the documentation of pituitary tumours, unlike other cancer types, is not required in the current Australian health landscape. This is an example of the inequity faced by patients with pituitary disease. We need data to help advocate, but without funding the inequity cycle continues.

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.

In fact, quality of life for some pituitary patients is on par with sufferers of rheumatoid arthritis and other serious medical conditions.

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 and other specialists 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 health system and determining which doctors are the most qualified to treat

pituitary tumours. In addition, limited funding within the public health system has led to serious delays in facilitating timely surgical treatment of these patients.

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

Pituitary Centres of Excellence comprise an international standard of care for pituitary patients but NSW and other jurisdictions in Australia are currently lagging behind with funding to establish such models.

In addition, research into pituitary medicine and clinical innovation undertaken in NSW does not currently receive any funding from the NSW Government, relying instead on donations.

### **About traumatic brain injury and pituitary deficiency**

Traumatic brain injury (TBI) affects approximately 1 in every 1000 NSW residents and can cause devastating health outcomes that may be permanent.

According to international data, 1 in every 3 patients with TBI will have pituitary deficiency, which may affect their rehabilitation and long-term health outcomes.

In Australia, we don't have the resources to screen all these patients and hence there are likely thousands of patients living with a TBI whose quality of life and health could be improved with pituitary replacement therapy.

### **Solutions**

**I propose three solutions** 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 and other pituitary conditions.

These solutions also align with the NSW Government's interests in:

- New models of care and technical and clinical innovations to improve health outcomes for the people of NSW, including but not limited to technical and clinical innovation, changes to scope of practice, workforce innovation, and funding innovation.
- the capacity and capability of the NSW Health workforce to meet the current needs of patients and staff, and its sustainability to meet future demands and deliver efficient, equitable and effective health services.

***Solution 1: Provide funding to properly establish NSW's only Pituitary Centre of Excellence at St Vincent's Hospital Sydney.***

This would:

- improve pituitary surgical training opportunities that arise from the concentration of pituitary surgical expertise
- ensure pituitary patients are managed by an experienced endocrinologist and outcomes of pituitary surgery are optimised

- reduce the numbers of patients requiring additional surgeries and treatments
- bring NSW's current model of care for pituitary patients in line with international best practice
- ensure continued excellence in pituitary patient care over the long-term in NSW.

Under this model of care, clinicians at NSW hospitals who diagnose patients with pituitary tumours would be required to refer these patients to State's only Pituitary Centre of Excellence for the possible best care.

***Solution 2: Establish a Pituitary Registry to maintain records of people with pituitary tumours and other pituitary conditions in NSW.***

The data captured within the registry would provide useful insights into the impact of pituitary tumours and other pituitary conditions, and how this has changed over time.

In addition, I propose making the notification of new pituitary tumour cases a requirement under the *Public Health Act 2010*.

By establishing Australia's first population-based pituitary registry (which includes data on size and type of pituitary tumours diagnosed, treatment and quality of care), researchers could determine suitability of screening programs for earlier detection of pituitary tumours.

***Solution 3: Provide funding for pituitary tumour research and clinical innovation.***

NSW Government funding for Australia's only dedicated research group for pituitary tumours and pituitary conditions would:

- protect Australia's only pituitary biobank and tumour samples needed for research
- support the staff who maintain this unique pituitary resource
- provide fellowships to upskill surgical and endocrine trainees
- provide a dedicated pituitary nurse who can offer more patient education and support
- enable genomic testing of pituitary tumours for better treatments.

In the past 50 years, no funding has been provided at the National Health and Medical Research Council (NHMRC) level for pituitary tumour research. The NSW Government has an opportunity here to further pituitary medicine and improve health outcomes for pituitary patients in NSW.

Yours sincerely



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