Submission
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INQUIRY INTO CURRENT AND FUTURE PROVISION OF HEALTH SERVICES IN THE SOUTH-WEST SYDNEY GROWTH REGION

Organisation: Thalassaemia & Sickle Cell Society of NSW

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Thalassaemia
& Sickle Cell
Society of NSW

Thalassaemia & Sickle Cell Society of NSW submission to the NSW Upper House Inquiry into the current and future provision of health services in the South-West Sydney Growth Region.

George Houssos
President

Submission to the Parliamentary Inquiry into the current and future provision of health services in the South-West Sydney growth region

The Thalassaemia and Sickle Cell Society of NSW (Society) appreciates the opportunity to lodge a submission to the Parliamentary Inquiry into the current and future provision of health services in the South-West Sydney Growth Region

We welcome this opportunity to play a constructive role in to advocate for the overdue improvement of health services in South Western Sydney.

At the outset, we acknowledging the general high standards of health care in NSW, especially when compared globally, however, we would like to see the state of NSW become the benchmark of care for sufferers of Thalassaemia, Sickle Cell and other Heamoglobinopathies and improve the level of consistency of treatment and care.

Thalassaemia and Sickle Cell are genetic blood disorders which require lifelong treatment.

The Thalassaemia and Sickle Cell Society of NSW was founded in 1978 to provide support services for parents and patients of sufferers of Thalassaemia and Sickle Cell.

At that time, patients diagnosed with one of these diseases were expected not to live beyond their teens. This was heartbreaking for parents and the medical staff, so with much love, enthusiasm and passion they formed the Thalassaemia and Sickle Cell Society of NSW to provide moral support to each other and just as importantly, raise money for research, medical treatment and equipment.

Only as a result of the commitment of key dedicated doctors, parents, and patients, today the standards and advancements in treatment means well treated patients can live normal, fulfilling lives with almost full life-expectancy.

Treatment is complex, life-long and intensive and must be supervised by specialised doctors. It requires a high level of compliance and monitoring. Treatment involves regular blood transfusions (3-6 week intervals), daily iron chelation and a complex arrangement of monitoring for supplementary complications and associated risks. This includes biennial and annual life long, monitoring of endocrine complications, cardiac health, the risk of diabetes, checking the health of eyes and ears. To do this, patients need regular and consistent access to specialist haematologists, MRI machines, pathology services and other specialist doctors and treatments.

Patients and their families also often need counselling and psychosocial support services to help them cope with this chronic disease and the associated complications which adds to the existing burdens of growing up.

In NSW there are five main locations of treatment:

- Sydney Children's Hospital
- Westmead Children's Hospital

- Prince of Wales Hospital (Adults treatment)
- Royal Prince Alfred (Adults treatment)
- Liverpool Hospital (Adults treatment)

There are also a few patients who are treated in Newcastle and Wollongong.

As a long-standing organisation who represents all of NSW, we have been able to witness firsthand the growing disparity of care between South Western Sydney and the treatment centres of the Eastern and Inner-City suburbs of Sydney.

While in society we try not to discriminate, Thalassaemia and Sickle Cell does. As a genetic disorder, it has a higher impact on specific ethnic groups. During the 1960's – 1990's it was prevalent in the countries of the Mediterranean, especially Greece, Italy, Malta and Cyprus. Since the 1990's there has been huge incidence in the Middle East, South and Eastern Asia and the Subcontinent. Africa has consistently had a high prevalence for Sickle Cell.

What this means for NSW and South Western Sydney? **As new migrant communities settle in South Western Sydney, the incidence and diagnosis of Thalassaemia and Sickle Cell has significantly increased, but the standard of health care provision and resources have not met this increased demand.**

Without proper and comprehensive treatment and the appropriate staffing resources to maintain the complex nature of treatment and compliance, patients are falling through the cracks and not receiving the same standard of care as elsewhere in Sydney. This leads to patients falling into high risk categories for health complications such as diabetes, cardiac failure, and shortened life-expectancy. **The current standards and resourcing of health care provision for Thalassaemia and Sickle Cell patients in South Western Sydney is failing to meet the needs of patients and is compromising the health outcomes for our members.**

Doctors, nurses and patients have observed a distinct disparity in health care between South Western Sydney and the rest of Sydney. As children transition from Westmead Children's hospital, many are reluctant, or refuse to transition to Liverpool Hospital. They would rather deal with the added burden of travel and fatigue, to be treated in the eastern suburbs or inner-city, than suffer the poor standards and inferior treatment in Liverpool Hospital.

At Royal Prince Alfred Hospital, 40% of patients are from South Western Sydney. Prince of Wales is seeing the numbers of patients from South Western Sydney constantly increase.

Transitioning the place of treatment for young adults is always difficult at the best of times. They are dealing with the general stresses of growing up, study and other life pressure. Having to face the poor standards in Liverpool makes it worse. This has a detrimental impact on their compliance with their rigorous treatment requirements.

With the exception of Liverpool Hospital, the other four main treatment centres listed above all have the benefit of fulltime haematologist and proper resourcing of senior nursing staff.

Clinical Nursing Consultants (CNC), who serve as a crucial liaison with haematologist and patients to closely monitor a patient's health status. They identify, anticipate and intervene if early signals appear of deteriorating health, and serve to coordinate and organise the complex and onerous routine health checks that are required for each patient. These test include MRI's, ultra sounds, Glucose Tolerance Tests, Bone Density tests and endocrine consultations.

Dedicated haematologist and CNCs are instrumental in compliance and therefore health outcomes for sufferers of Thalassaemia and Sickle Cell.

Unfortunately, Liverpool Hospital lacks these full-time resources. This means that visits to specialists become more infrequent and difficult. Doctors and nursing staff are so overstretched the do not have the capacity to reach out to patients falling behind for the crucial early interventions that patients at other hospitals receive. Patients start to slacken with treatment and there is often a detrimental lag of time before the consequences can present themselves, sometimes if compliance of care is so neglected, they can be fatal over a period.

The treatment for Thalassaemia and Sickle Cell is lifelong. The quality of treatment is directly linked to health outcomes and life expectancy. That is why improving the standard of care is critical.

Health districts are creating islands of care, which is leading to drastic contrast in the quality of care. This means that patients in South Western Sydney are receiving less care than patients treated at other hospitals. We need this parliamentary inquiry to make recommendations to ensure all NSW hospitals provide the same level of care to Thalassaemia and Sickle Cell patients.

Recommendations
The Thalassaemia and Sickle Cell Society of NSW calls on the committee to make the following recommendations to ensure all patients across NSW received the same level of care:

- **Increase the resourcing of senior nursing staff including Clinical Nursing Consultants.**
- **Establish a dedicated comprehensive care centre in Liverpool for both weekday and weekend/after hour service to meet the growing demands.**
- **Provide a haematological service at Campbelltown Hospital**
- **Greater resourcing for obstetrics and pre-natal service for people with Thalassaemia and Sickle Cell.**
- **Provide free MRI tests for T2* scans and feriscans of heart and liver.**

George Houssos
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