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Committee Secretary
Senate Standing Committees on Community Affairs
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Dear Committee Secretary

Thank you for the opportunity to provide a submission to the Senate Standing Committees on Community Affairs' Inquiry into *Equitable access to diagnosis and treatment for individuals with rare and less common cancers, including neuroendocrine cancer* (the Inquiry).

The Tasmanian Government is committed to supporting all Tasmanians to access the best possible treatment and care, including those living with rare and uncommon cancers. Public cancer services are provided through the Royal Hobart Hospital (RHH) in the south of our state, and the Northern Cancer Centre in the North and North West. The Northern Cancer Centre integrates the cancer services, expertise and infrastructure available across the North and North West, allowing Tasmanians living in these regions to receive better access to high quality, timely cancer care.

Children and young people with cancer receive care through the Tasmanian Paediatric Oncology Service. This is a specialist statewide service which provides holistic care for children and young people with malignant blood cancers, solid cancerous tumours of the muscles, bones or organs and brain tumours. The Paediatric Oncology Service is based in the RHH but, where possible, our oncology team communicates with services closer to the child's home to organise treatment and reduce the need to travel for necessary care.

Tasmanians with neuroendocrine tumours receive comprehensive, world-class treatment. In 2022, approximately 85 individuals were diagnosed with a neuroendocrine tumour in Tasmania, which equates to around 3.4 per cent of all cancers diagnosed in our state. These Tasmanians are seen at our dedicated statewide Endocrine Neoplasia Clinic at the RHH, which is recognised both nationally and internationally for its work and research into neuroendocrine tumours. Additionally, the Endocrine Laboratory at the RHH is a national reference centre for highly specialised neuroendocrine tumour markers (such as Chromogranin A).

The diagnosis and treatment of rare and less common cancers often requires highly specialised equipment and technologies. Tasmania is a small jurisdiction, by both land mass and population size, compared with other Australian jurisdictions. As a result, there are some highly specialised services targeted at rare and less common cancers that our health system does not have the demand to support.

The Tasmanian Government is committed to ensuring all Tasmanians have access to the right care for their needs, and we have arrangements in place for when this care is not available within our state. Where our health system does not have the equipment or technology required to care for a patient with a rare or less common cancer, we may refer them to a mainland hospital. The hospital that a patient is referred to is based on several factors including the patient's personal support network, the clinician's professional network and the type of treatment required. For example, our clinicians often refer patients who require a peritonectomy (which is not available in Tasmania) to St George Hospital in New South Wales, which has a well-established peritonectomy unit. We also have a partnership with the Royal Melbourne Hospital for the provision of bone marrow allografts. Children with cancer who require complex treatment unavailable in Tasmania are referred to the Royal Children's Hospital or the Peter MacCallum Cancer Centre in Melbourne. Care is then shared between these interstate services and the Tasmanian Paediatric Oncology Service.

Improving the health outcomes and lives of all people affected by cancer living in Tasmania, including those with rare and less common cancers, is a priority for the Tasmanian Government. In June 2023, we released the *Long-Term Plan for Healthcare in Tasmania 2040* (the Long-Term Plan), which provides system-wide direction and strategy for the delivery of health services to achieve a sustainable, integrated and balanced health system. As part of the Long-Term Plan, we have committed to the development of a Tasmanian Cancer Plan, which will support the Department of Health in improving the health outcomes and lives of all Tasmanians affected by cancer. Development of the plan will commence later this year and will be informed by the Commonwealth Government's *Australian Cancer Plan 2023-2033* which is expected to be released later this year.

Rare diseases (including rare and less common cancers) may have a genetic cause, making genetic diagnosis critical to finding appropriate management or treatment. However, conducting genomic testing in a timely manner can be challenging, particularly in remote and rural areas. To help address this challenge, we are undertaking a Tasmanian Rare Disease Diagnostic Pathways Project. This Project, which has been enabled thanks to funding from Australian Genomics under the *Australian Genomics Grant Program Proposal 2021-23*, will map existing diagnostic pathways for rare disease patients in Tasmania, explore community need and co-design new diagnostic pathway models for Tasmanians with rare diseases. Additionally, under the Long-Term Plan, we are establishing a Genomics Clinical Network, which will allow us to harness genomic technologies in Tasmania's health system. This will improve our ability to use genome sequencing to stratify cancers and understand how a person is likely to respond to treatment.

In addition to ensuring equitable access to diagnoses and treatment, Tasmania is committed to undertaking clinical trials on rare and less common cancers. These trials both enhance local cancer research and help in identifying new treatments which will benefit Tasmanians.

Both our Northern Cancer Service and our cancer services in the south have active clinical trials units with a portfolio of both collaborative group and Pharma run trials, aimed at providing opportunities for participants with rare cancers to access a clinical trial locally where possible. Our Department of Health has participated in 17 clinical trials on rare cancers and tumours, including one study focussed on neuroendocrine cancer. Tasmania's participation in this research has been in collaboration with a variety of partners, such as the University of Sydney, Monash Health and Janssen-Cilag.

In September 2022, the Tasmanian Government partnered with the Peter MacCallum Cancer Centre. This partnership is allowing us to deliver world-leading cancer treatment and best practice recovery supports, as well as increasing the opportunities for Tasmanians with cancer to participate in clinical trials for rare types of cancers.

We are also participating in a number of clinical trials specifically focussed on children and young people with cancer, including those with rare and less common cancers. With no prevention for childhood cancer, the only way to improve outcomes is through advances in medical research. In September 2021, we committed \$600 000 over three years to the Children's Cancer Clinical Trials Unit, which is

providing continued local access to clinical trials by Tasmanian children with aggressive forms of cancer. Since the unit was established in 2017, Tasmanian children have been able to access new therapeutic options for a number of rare cancers (such as Hodgkin's Lymphoma, brain cancers and refractory solid tumours) by participating in clinical trials.

Additionally, the RHH is participating in the ZERO 2 Childhood Cancer Clinical Trial, which aims to improve the health outcomes of all children and young people with cancer using precision medicine. The trial is currently enrolling patients into high risk, rare or central nervous system cancer cohorts, and will later open to all patients with paediatric cancers.

Moving forward, Tasmania would welcome the opportunity to participate in clinical trials including (but not limited to) those relating to surgical and radiological interventions, nuclear medicine, chemotherapy and related agents, supportive care and patient reported outcomes for rare tumours – including neuroendocrine tumours. This will allow us to continue improving cancer research, education and treatment for all Tasmanians impacted by rare and less common cancers.

Yours sincerely

Hon Guy Barnett MP
Minister for Health