NeuroEndocrine
Cancer Australia

NeuroEndocrine Cancer Australia

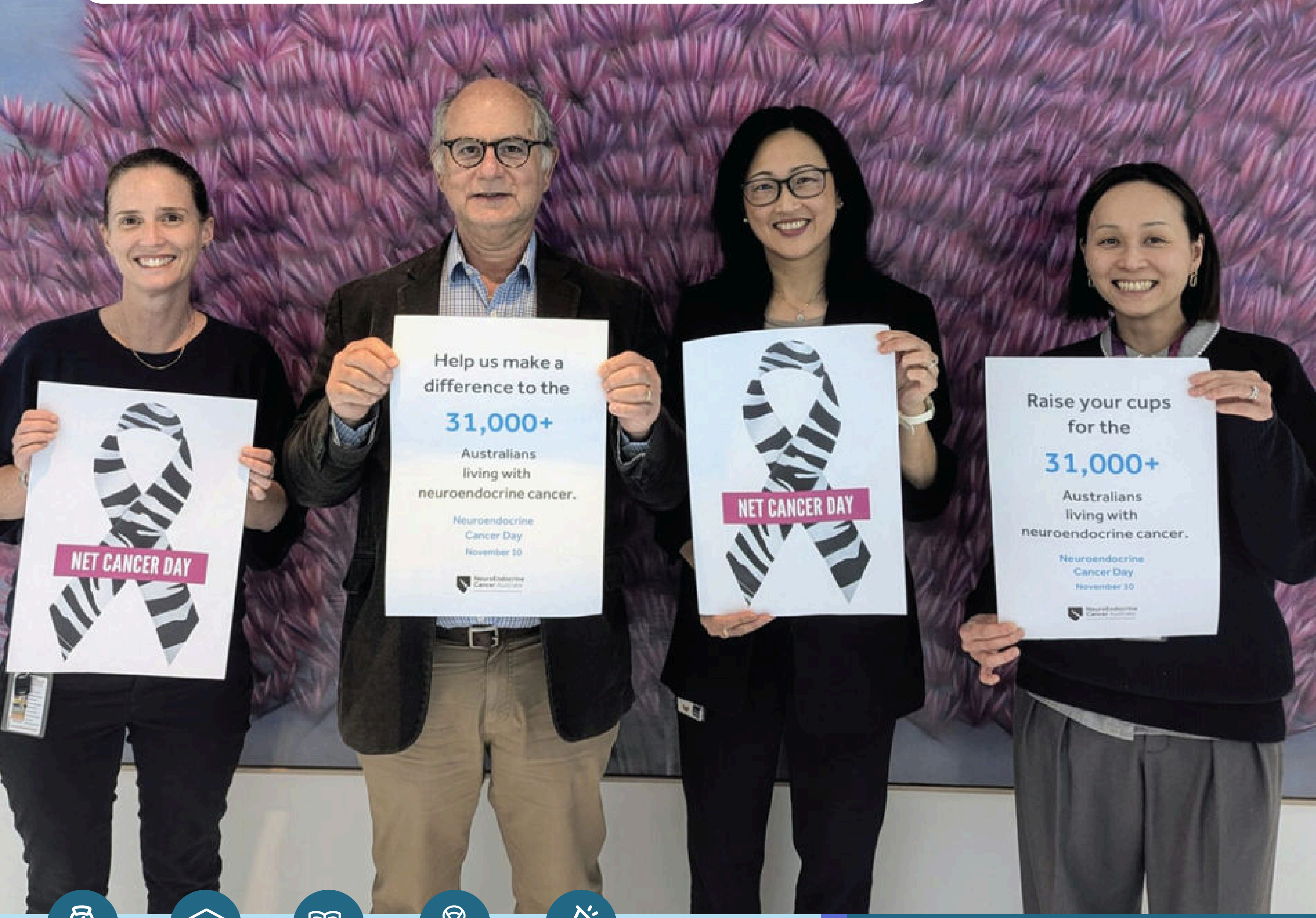
# MP Briefing

About Us

# NeuroEndocrine Cancer Australia (NECA)

is the only Australian charity solely dedicated to improving awareness, understanding and outcomes for people living with neuroendocrine cancer.

Our purpose remains as vital now as it was 16 years ago: to achieve earlier diagnosis and ultimately find a cure for many.



# Contents

# Over the Past Decade, NECA has:

## Funded

millions of dollars in patient support and resources

## Established

a national NET Nurse Helpline and facilitated support groups across Australia

## Advocated

for improved access to diagnostics and treatments

## Supported

clinical trials that advance NET care and understanding

# What is Neuroendocrine Cancer?

Neuroendocrine cancers, are a group of cancers that begin in neuroendocrine cells.

These specialised cells are found throughout the body and help regulate essential functions by producing hormones. NETs can develop in many organs, most commonly in the gastrointestinal system, pancreas and lungs.

Neuroendocrine cancers are often missed or diagnosed late because their symptoms frequently mimic more common conditions.

Many people experience issues such as abdominal pain, diarrhoea, fatigue, flushing or unexplained weight changes. These are easily mistaken for gastrointestinal disorders, stress, asthma or menopause. As a result, Australians with neuroendocrine cancer often undergo years of misdiagnosis before receiving the correct answer.

Neuroendocrine cancer is Australia’s 7th most diagnosed cancer. Despite this, public awareness remains low and symptoms are often misunderstood within the community and across the health system.

1 Australian is diagnosed with a Neuroendocrine Tumour every 90 minutes

The average Australian waits over 5 years for a correct diagnosis

30 % of patients are diagnosed in the Emergency Department

**31,000+**
australians living with Neuroendocrine Cancer

**5,755+**
australians are diagnosed annually

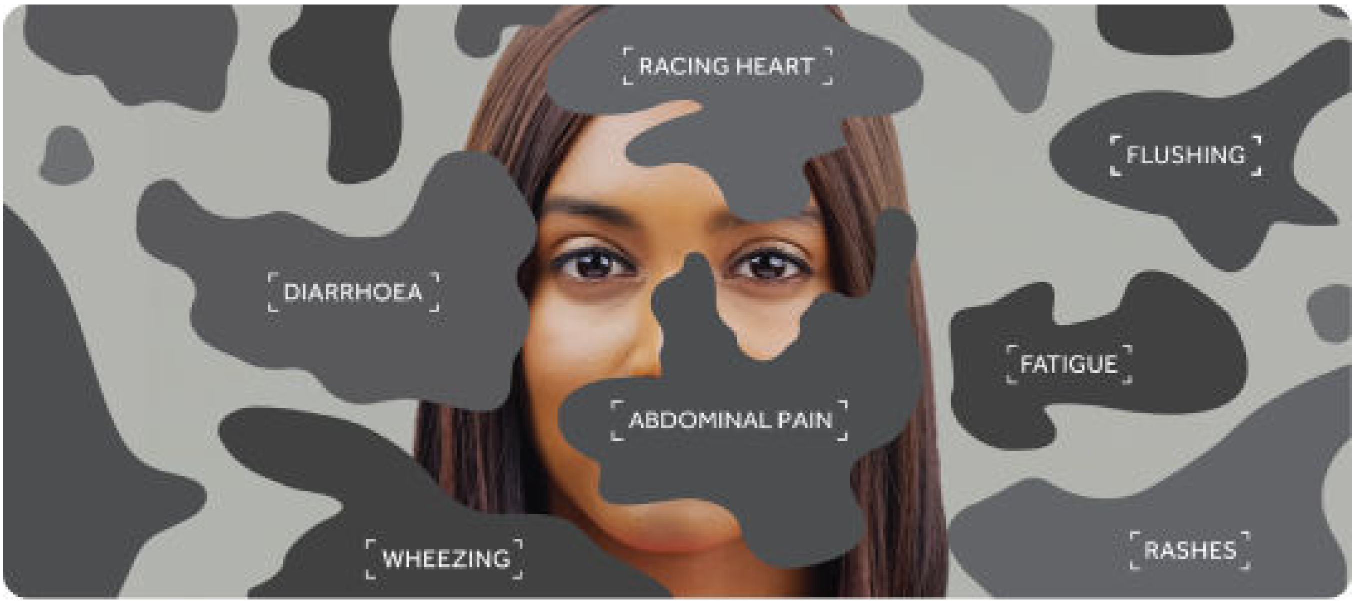
**1 in 48**
australians have a chance of developing a NET

**1 in 2**
patients report being originally diagnosed with something else

**1/3**
of patients report cost is a consideration when choosing cancer treatment

**60%**
of patients are at stage 4 by the time of diagnosis

# Symptoms



# Key Priorities for NECA

01 **NET Nurse Funding**

02 **HTA Reform**

03 **466 Days: Faster Access Push**

04 **Radiopharm Access**

05 **Clinical Trial Expansion**

06 **Inquiry Implementation Tracking**

# The Challenge

Despite being relatively common, neuroendocrine cancers remain under recognised and difficult to diagnose. Patients frequently cycle through primary and acute care systems before receiving the right investigations. Access to PET imaging, PRRT and NET specialist clinicians is not consistent across states. There is a NET Optimal Care Pathway nationally however many healthcare professionals do not know about it and therefore, it is under utilised and some states have no dedicated neuroendocrine cancer nursing support.

These gaps lead to avoidable hospital use, late stage diagnoses and inequitable outcomes.

# NECA Recommends

**1. Fund NET specialist nurses nationwide**

Establish and sustain neuroendocrine cancer specialist nursing in every state and territory, beginning with Tasmania, to ensure coordinated care and earlier support for all Australians with neuroendocrine cancer.

**2. Improve access to NET diagnostics**

Increase availability of Ga68 and other radioisotopes for PET imaging and ensure clear, consistent referral pathways so patients are diagnosed faster and more accurately.

**3. Strengthen access to life saving treatments**

Reduce time to approval for therapies, streamline TGA, PBS processes and introduce Bridging Funding to ensure access to life saving treatments is expedited.

**4. Reform radiopharmaceutical assessment pathways**

Adopt a parallel and fit for purpose pathway for radiopharmaceuticals, aligning with Senate Inquiry recommendations and reducing unnecessary HTA delays.

**5. Expand NET clinical trial access**

Increase Australian inclusion in global clinical trials and ensure clinicians are included in clinical trials conversations. Invest in additional trial sites and participation pathways so neuroendocrine cancer patients can access emerging treatments and contribute to the evidence base.

**6. Deliver on Inquiry commitments**

Implement accepted Senate Inquiry recommendations with measurable progress, particularly those related to diagnosis, treatment equity and research investment.

**7. Ensure NET consumer involvement across policy and HTA**

Embed NET consumer expertise in all HTA, policy, cancer plan and pathway processes that shape treatment access and care.

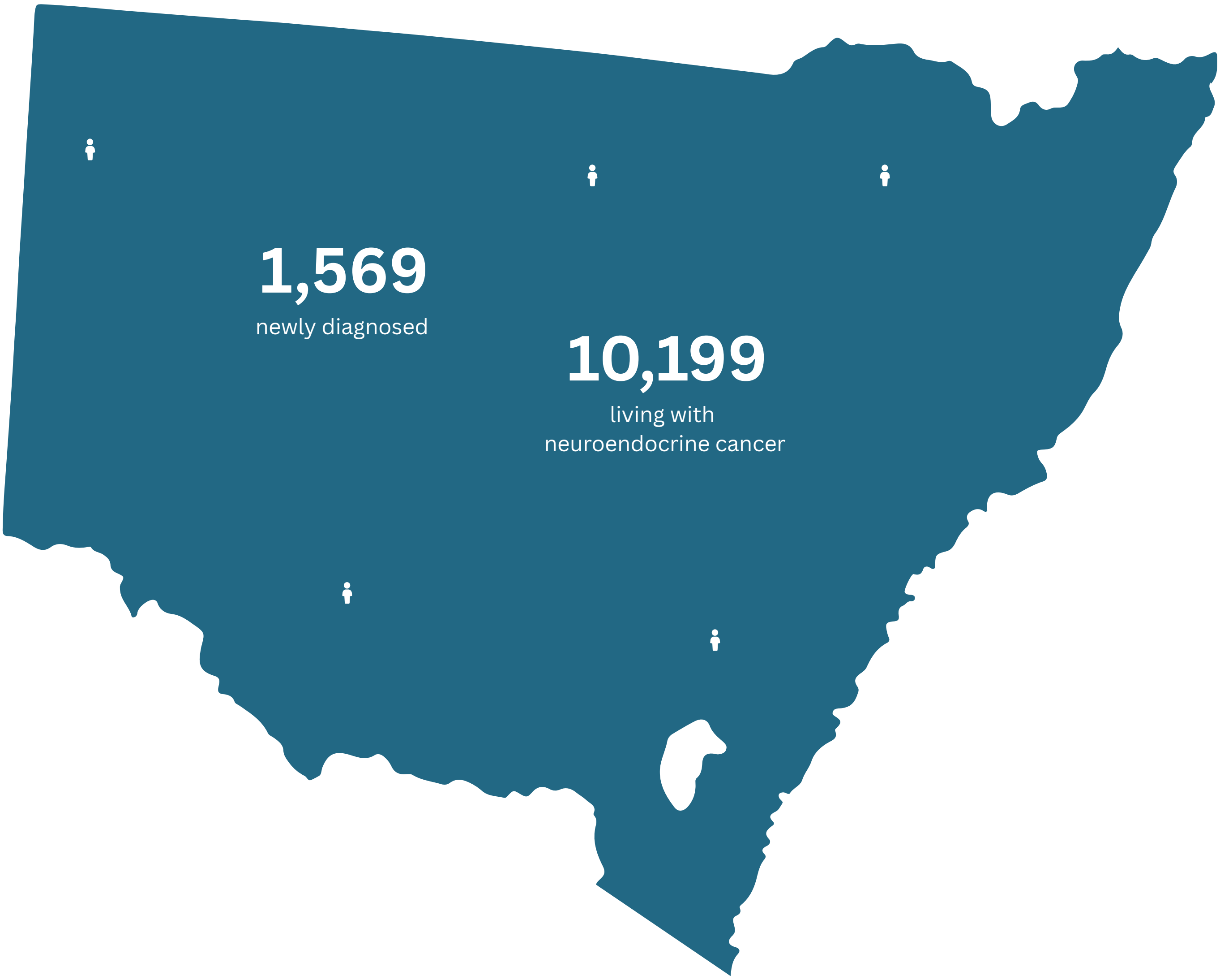
# Policy Context

**This briefing aligns with:**

- National Cancer Plan priorities
- State and territory cancer plans
- The Senate Inquiry into equitable access to diagnosis and treatment for rare and less common cancers
- HTA Review recommendations related to consumer voice, evidence flexibility and rare cancers
- Existing government commitments to navigation, statewide cancer services and improved imaging access

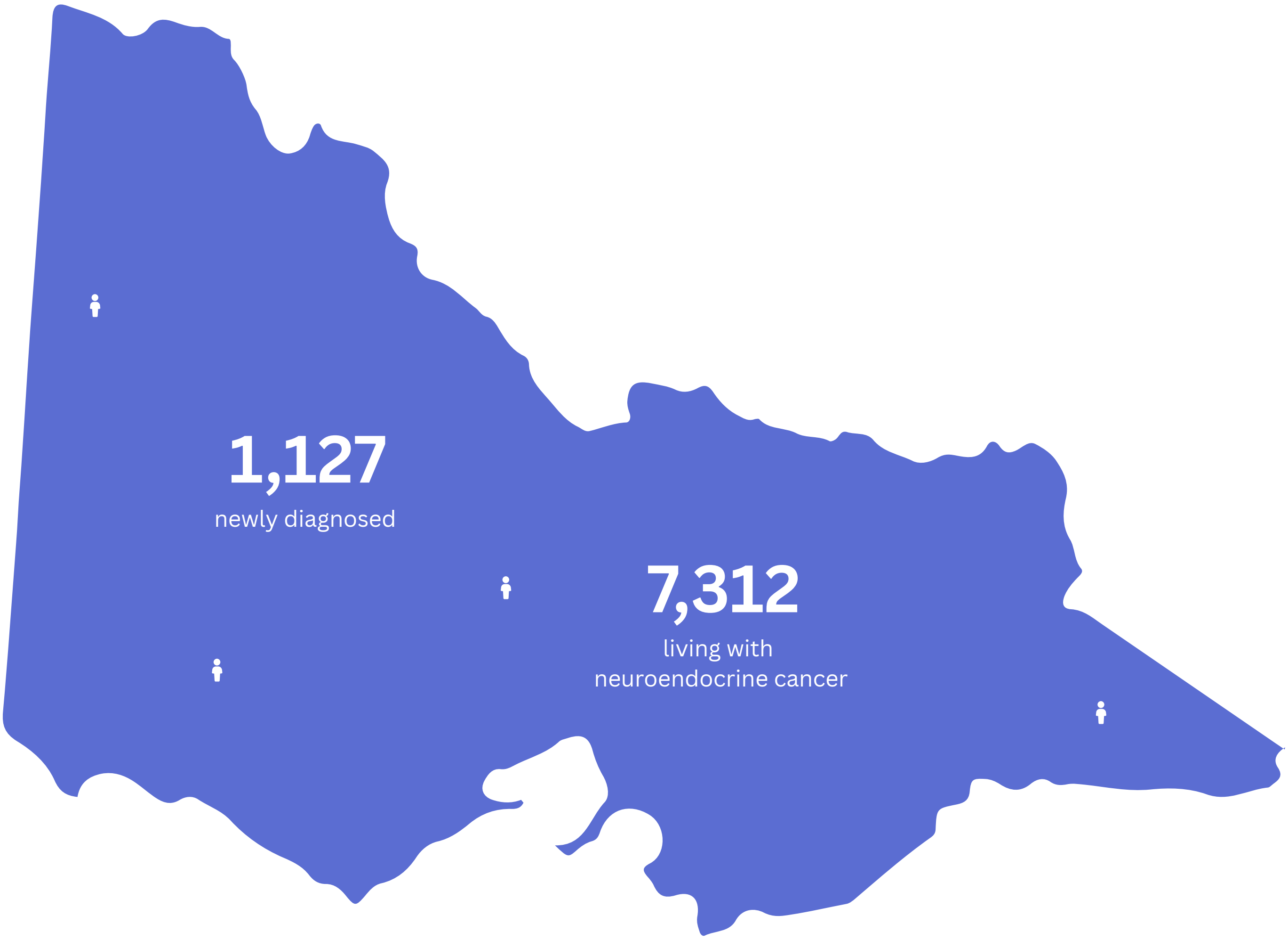
# State Snapshots

# NSW



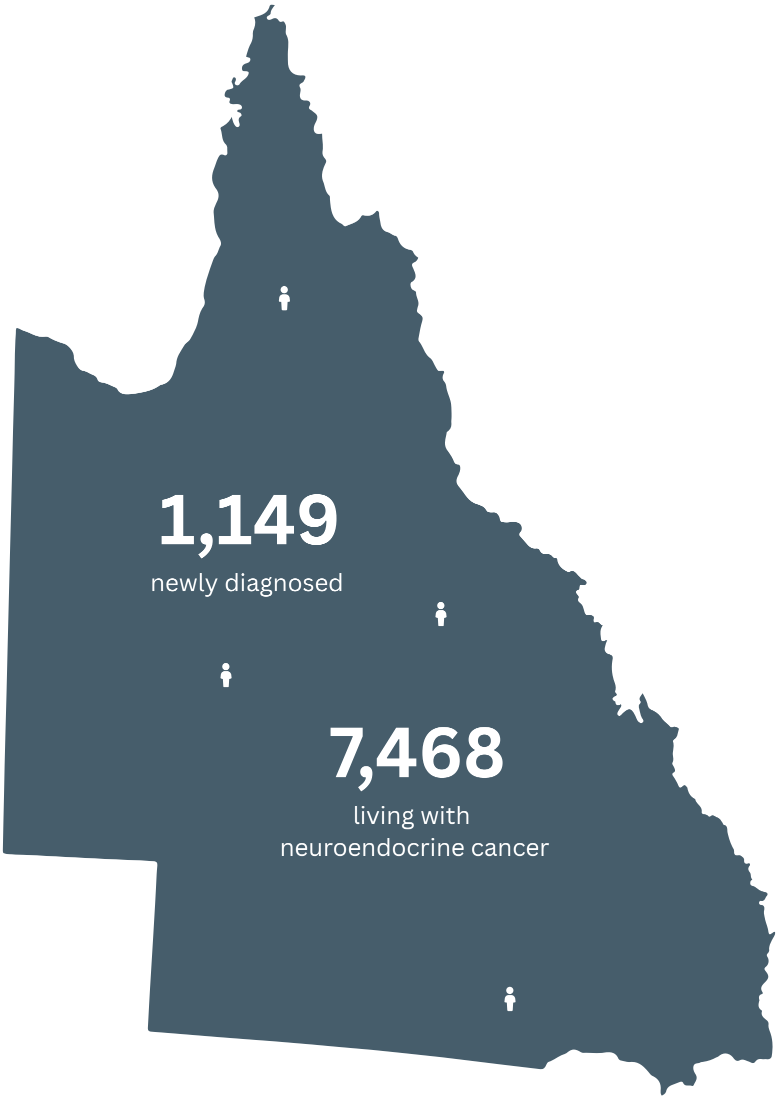
> **I experienced a year of ‘I don’t know what’s wrong with me, but something is up. The ongoing assumption was that I was simply going through menopause.**
>
> —**Bronwyn Wallace** (Manning Valley)

# Victoria



> I went to the local GP because I couldn’t burp... I was feeling fine and thought that this was a total waste of the doctor’s time.
>
> —**Daniel Renfrey** (Melbourne)

# Queensland



**1,149**

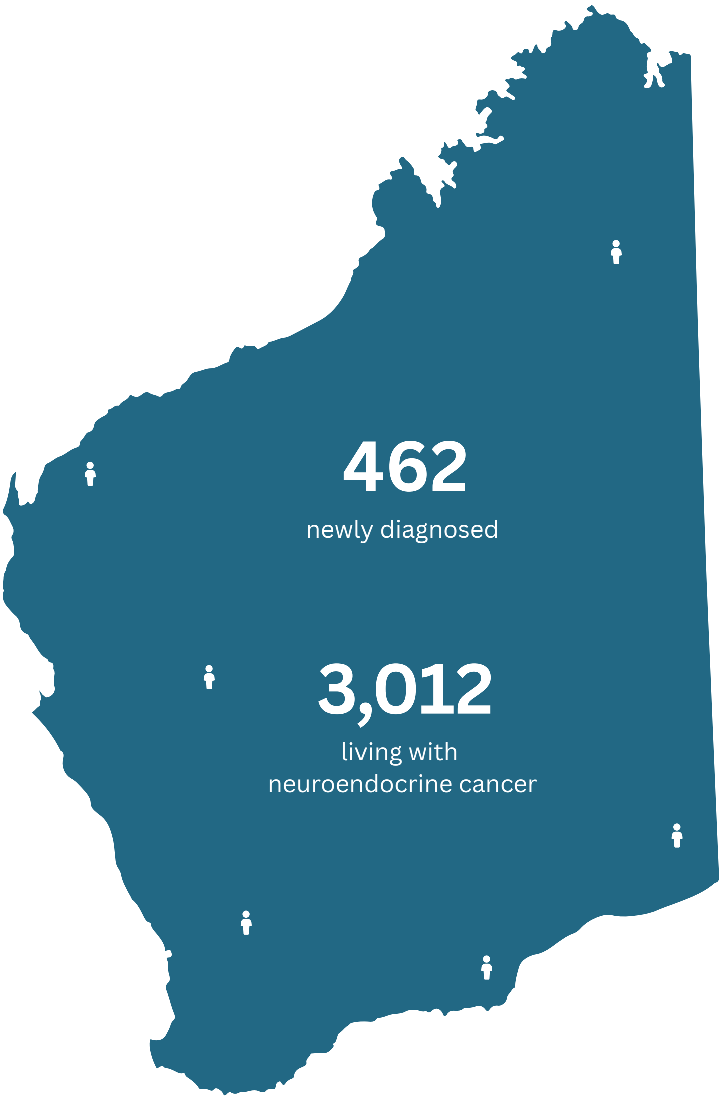
newly diagnosed

**7,468**

living with
neuroendocrine cancer

> **I'm a 36-year-old mum of three little humans – things like this just don't happen to people like me. Until all of a sudden it does, and everything changes.**
>
> —**Cassie Miller** (Sunshine Coast)

# Western Australia



**462**

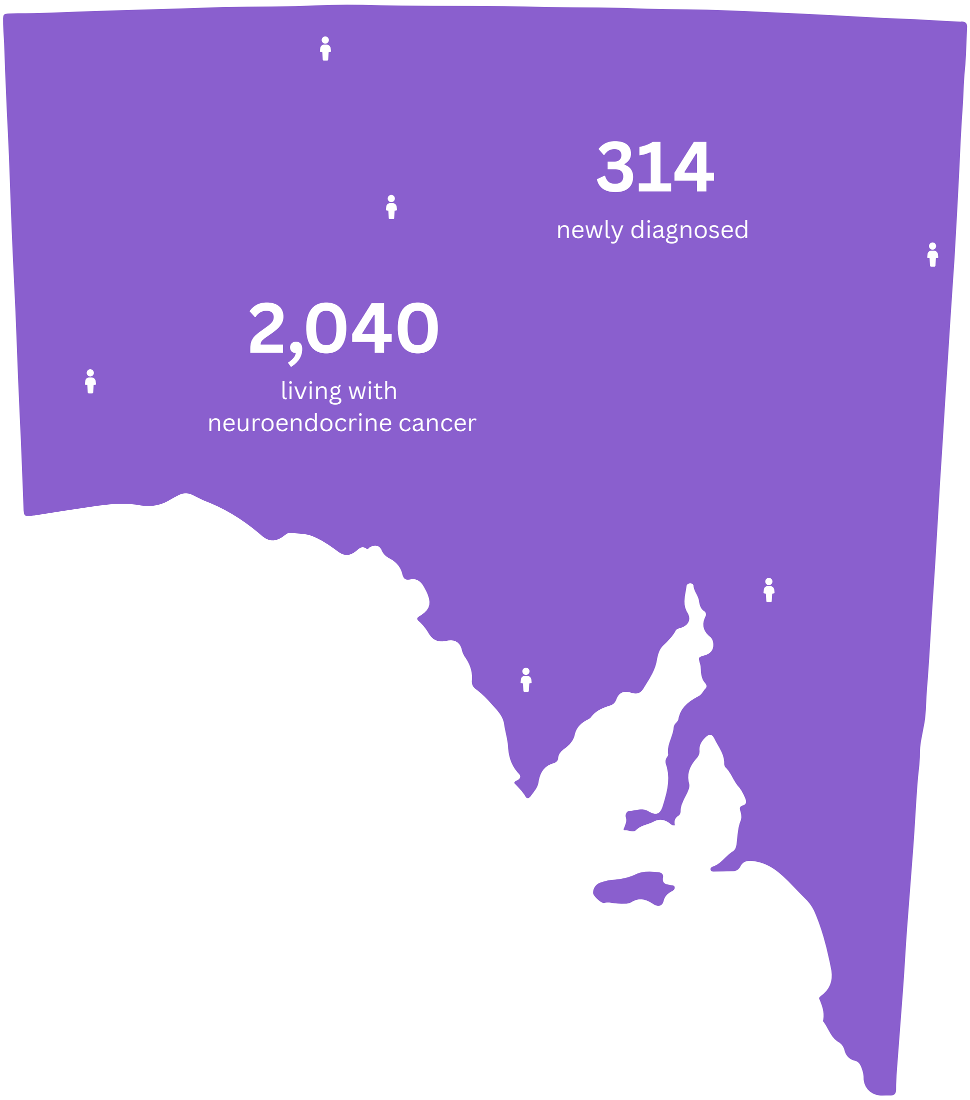
newly diagnosed

**3,012**

living with neuroendocrine cancer

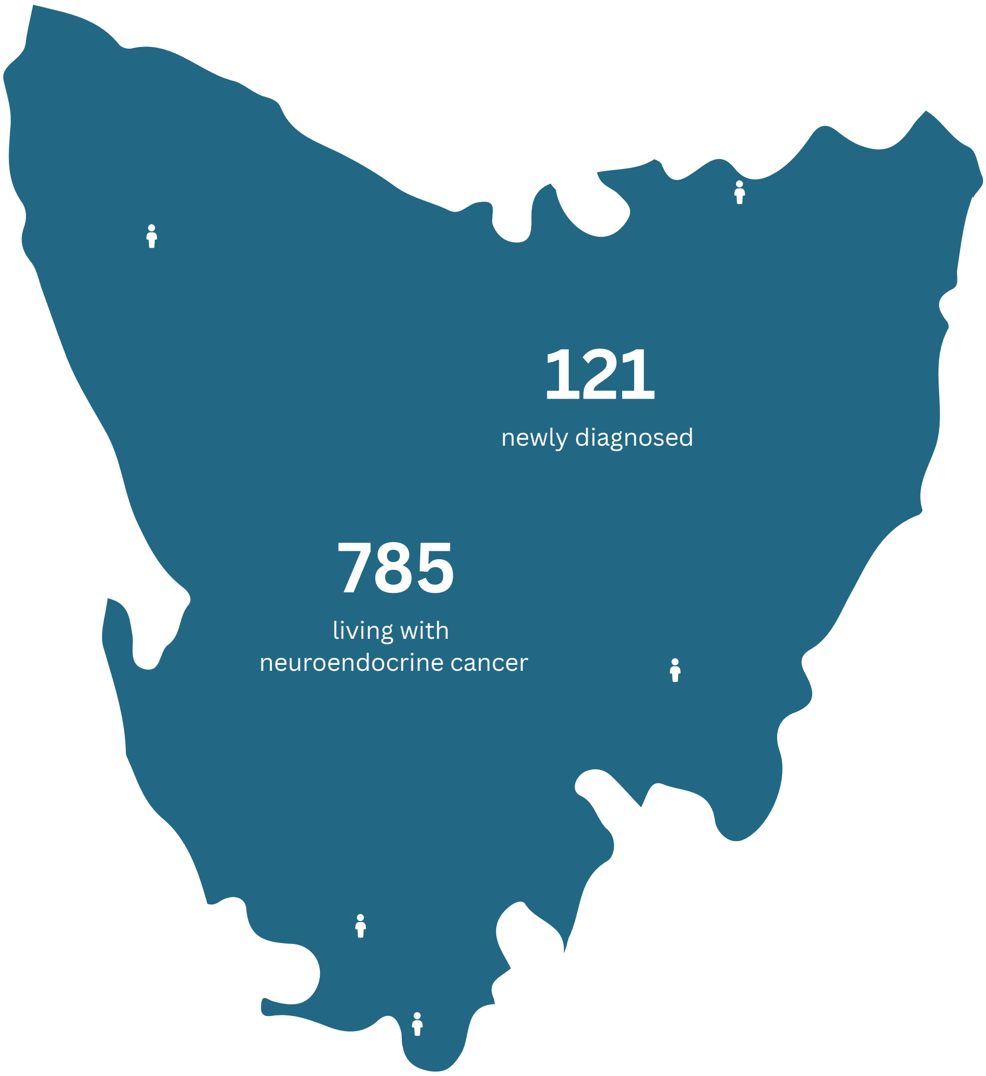
> **They found a tumour about the size of a tennis ball on my pancreas… It's a shame that it takes a diagnosis like this to change the way people live their life.**
>
> —**Mel Taylor** (Hannans)

# South Australia



> **A week later, the primary neuroendocrine tumour was removed, the diagnosis was confirmed but then came the word I had been dreading, metastatic.**
>
> —**Karen Vial** (Adelaide)

# Tasmania



**121**

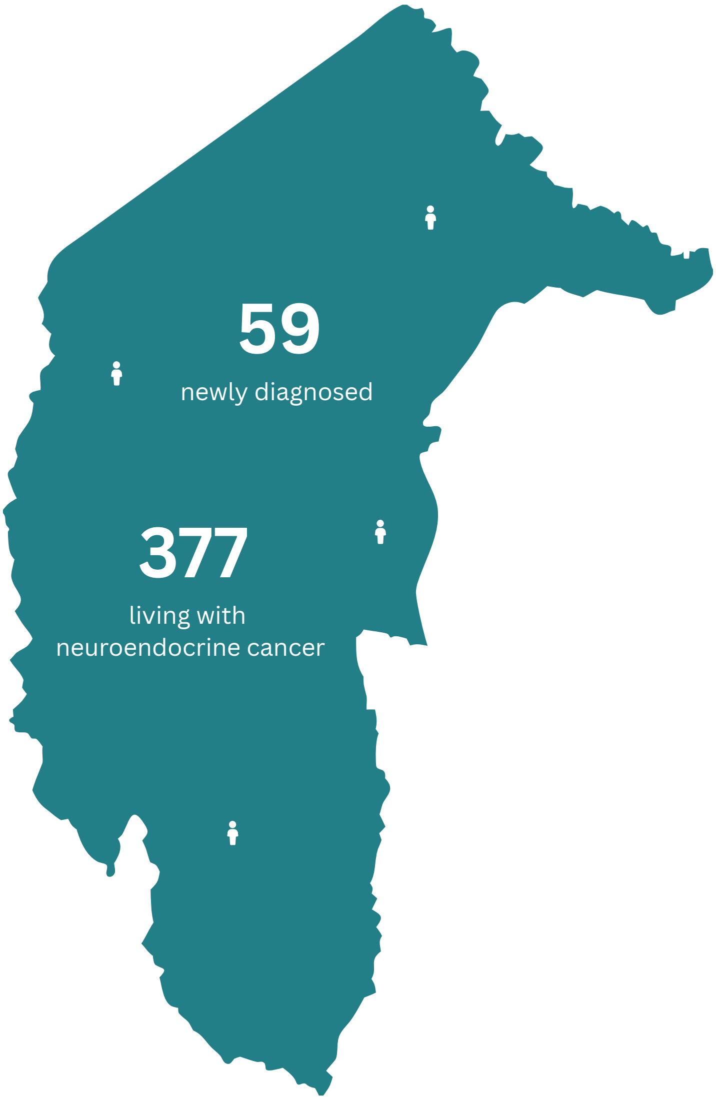
newly diagnosed

**785**

living with neuroendocrine cancer

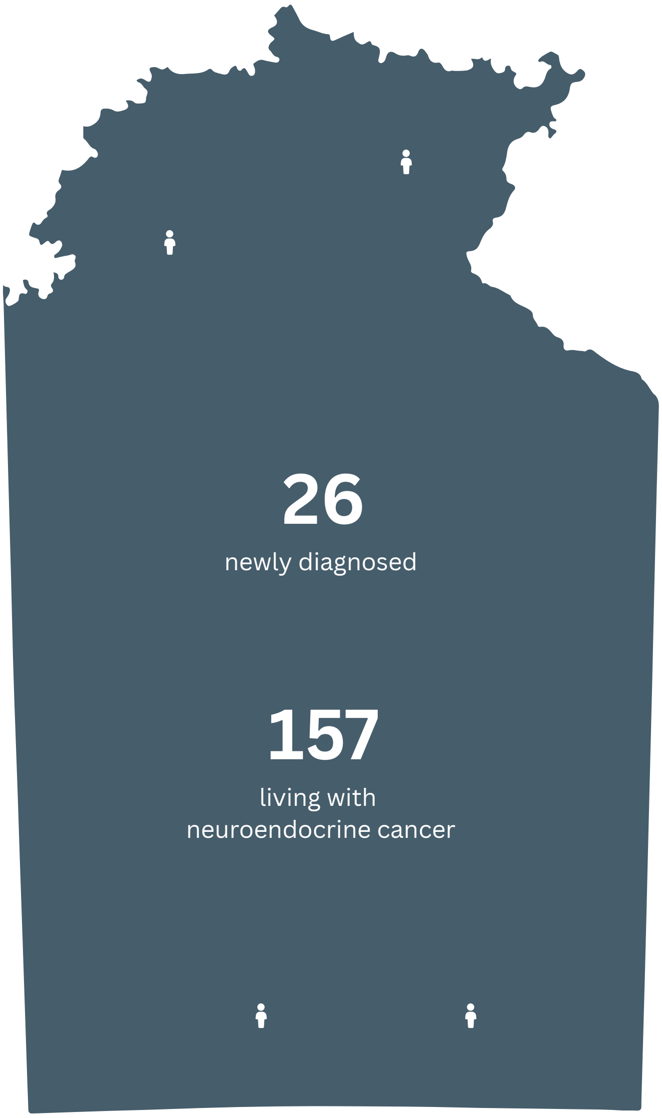
> **The hardest part is knowing that if I had a different type of bowel cancer, these same treatments would be fully funded by the Australian government.**
>
> **—Lauren Rayner** (North West Coast)

# Australian Capital Territory



> **What has been difficult is how little is known about neuroendocrine cancer, both in the community and even among some healthcare professionals.**
>
> **—Roxanne Coughlin** (Canberra)

# Northern Territory



26

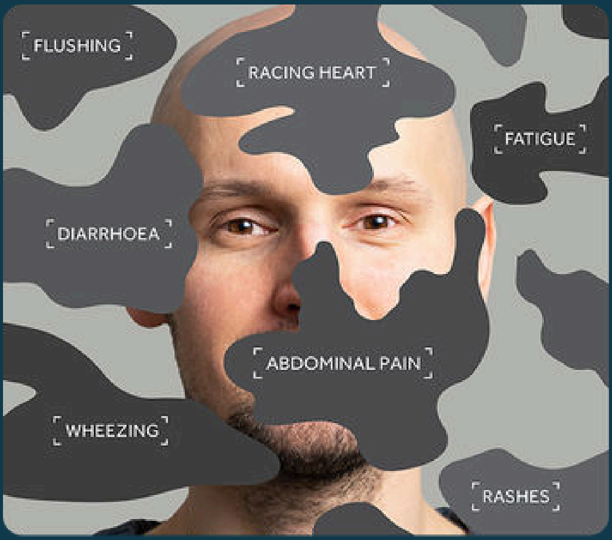
newly diagnosed

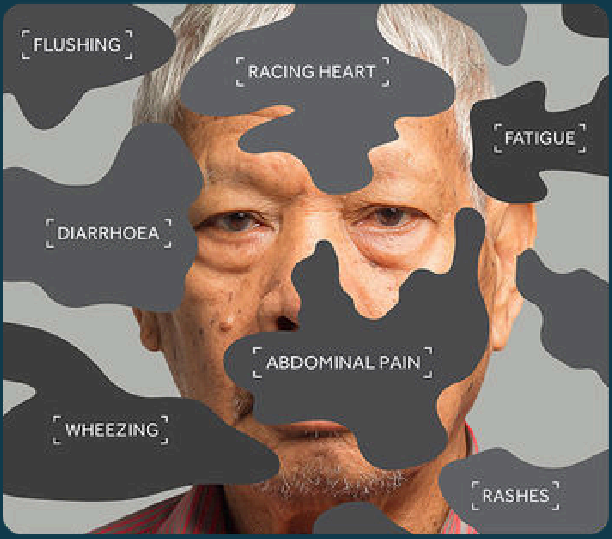
157

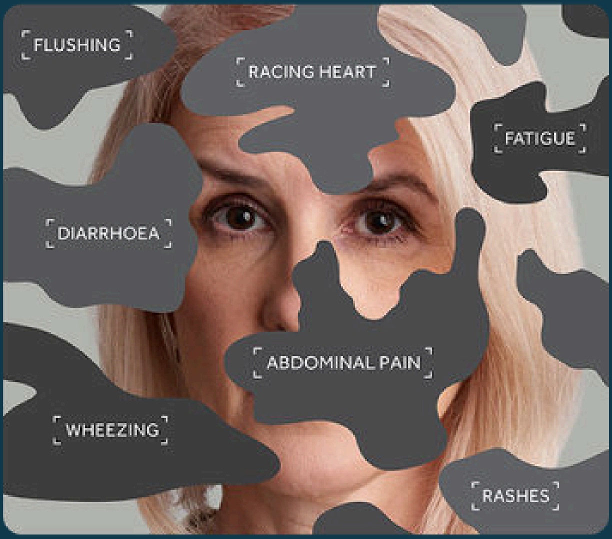
living with
neuroendocrine cancer

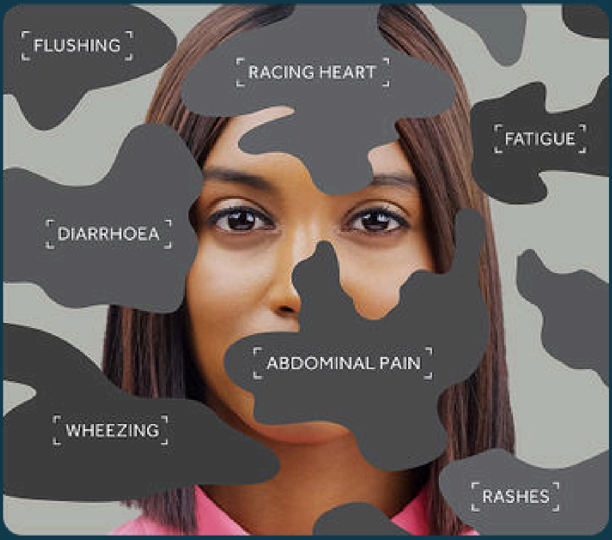
> I find it very difficult that just because my cancer is not in my breast I cannot have access to the same activities and support services as someone with breast cancer.
>
> —**Suzanne Stewart** (Darwin)

# Downloadable One Pagers









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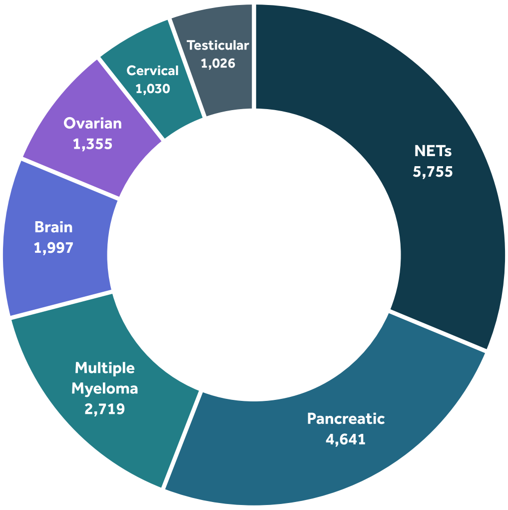
Cancer Australia

# Make neuroendocrine cancer Specialist Nurses Available Nationwide

Despite clear recommendations from the Senate Inquiry, most Australians with neuroendocrine cancer still have no access to a specialist neuroendocrine cancer nurse. These nurses are essential for improving outcomes, reducing hospitalisations, and supporting patients through complex care. Yet access remains limited, and current funding is short-term and insufficient to meet national demand.

## Thousands Diagnosed-Yet Still Overlooked



**Number Of Australians Diagnosed In 2024**

30% of patients live 300 klm or more from the closest Centre of Excellence

1 in 55 Australians have a chance of developing a NET

**7th**
Neuroendocrine Cancer is Australia's 7th most commonly diagnosed cancer

31,000+ Australians are living with NETS

Patients have a 53% 5 year survival rate

1 Australian is diagnosed with a Neuroendocrine Tumour every 90 minutes

The average Australian waits over 5-7 years for a correct diagnosis

**1 in 2**
patients are orignally diagnosed with something else

**60%**
of patients are at stage 4 by the time of diagnosis

## Your Role in Driving Change

### Why it Matters

- Specialist neuroendocrine cancer nurses provide expert care, improve outcomes, and reduce hospital admissions.
- Specialist nurses deliver life-changing care, especially in rural areas.
- Current funding ends in 2027, with no long-term guarantee.
- Demand for specialist nurse services has quickly exceeded capacity, highlighting the urgent need for national expansion and sustained funding.

### What We're Asking From You

- Fund a national rollout of the neuroendocrine cancer nursing program.
- Secure ongoing investment for NECA's clinical support team.
- Ensure access to nurses in every state and territory.

**Every year, over 5,000 Australians are diagnosed with neuroendocrine cancer.
They deserve better. Let's move from talk to treatment.**

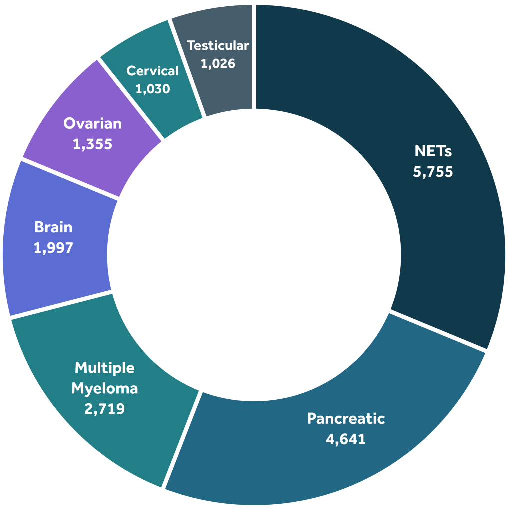
Contact NeuroEndocrine Cancer Australia ciara@neuroendocrine.org.au | neuroendocrine.org.au | (03) 8677 0905

**NeuroEndocrine Cancer Australia**

# Amplify the Patient Voice in Research and Policy Development

People with neuroendocrine cancer remain underrepresented in the research and decisions that shape their care. Their lived experience must be embedded in policy, research, and innovation, from diagnosis to survivorship.

## Thousands Diagnosed-Yet Still Overlooked



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## Your Role in Driving Change

**Why it Matters**

- Research is limited in reflecting the true burden of neuroendocrine cancer.
- Patients are excluded from priority-setting and policy design.
- Genomic and real-world data are underused in driving better care.

**What We're Asking From You**

- Back patient-led research and funding that reflects need.
- Support genomic profiling and real-world evidence use.
- Make patient experience central to cancer policy.

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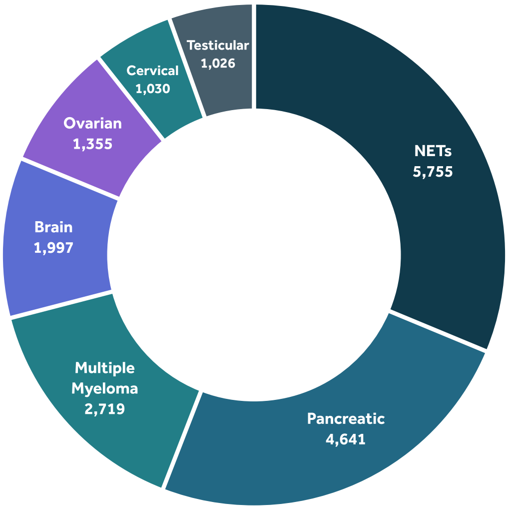
# Still waiting: Government response delivered, action overdue

The Senate Inquiry into rare and less common cancers, including neuroendocrine cancer, made 41 recommendations for urgent reform in 2024. While the government has now issued its response, patients are still waiting for meaningful action. Delays in implementing these recommendations mean delays in diagnosis, treatment and support. Time is passing, lives are affected, and the opportunity to fix long-recognised gaps in neuroendocrine cancer care is slipping away.

## Thousands Diagnosed-Yet Still Overlooked



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## Your Support Matters

### Why it Matters

- Delays in diagnosis average 5–7 years.
- Patients are misdiagnosed, undertreated, and underserved.
- Care is fragmented and specialist access is limited.
- The Senate Inquiry and 2021 New Frontiers report already laid out what's needed. What's missing is action.

### What We're Asking From You

- Support delivery of the Senate Inquiry commitments by calling for a clear, staged implementation plan with transparent progress milestones.
- Champion equitable access to diagnosis, treatment and specialist support, particularly for regional and rural Australians who face the longest delays.
- Work with NeuroEndocrine Cancer Australia to embed lived experience into cancer policy design, decision making and implementation.

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