



Donor Report 2022/2023



The Year in Review

A foreword from our CEO, **Meredith Cummins**

NECA, as an organisation, is dedicated to ensuring our patients have access to information, support, and the “best cancer care”. We are a small organisation that aims high for our NET community. We are able to achieve so much through your generous contributions and we are truly appreciative of your support-THANK YOU from us all!

Our goals for 2023/2024:

- Optimal Care Pathway promotion
- National Awareness Campaign
- Expanding the NET Nurse Support Service with additional nurses across Australia
- Expand and fund the PLANET registry to more sites across Australia
- Increase education and resources to the general and healthcare professional communities

Moments To Celebrate

NeuroEndocrine
Cancer Australia

LIVING WITH NETS PROGRAM



October 2022

NECA Launches free Living with NETs Program, now running 3 times per year



January 2023

World First! Neuroendocrine Tumour Optimal Care Pathway launched

October 2022

NET Patient Rob Hammond runs inaugural Race for a Cure Fundraiser and raised over \$47,000



February 2023

Norman Family Trust generously sponsor a Nurse Educator/Project Officer so NECA now have an expanded team and one resource working full time to educate HCPs



2022
**PRIME
AWARDS**

**WINNER
BEST NGO**
(non-government organization)

November 2022

NECA named NGO of the Year by the peer nominated Prime Awards

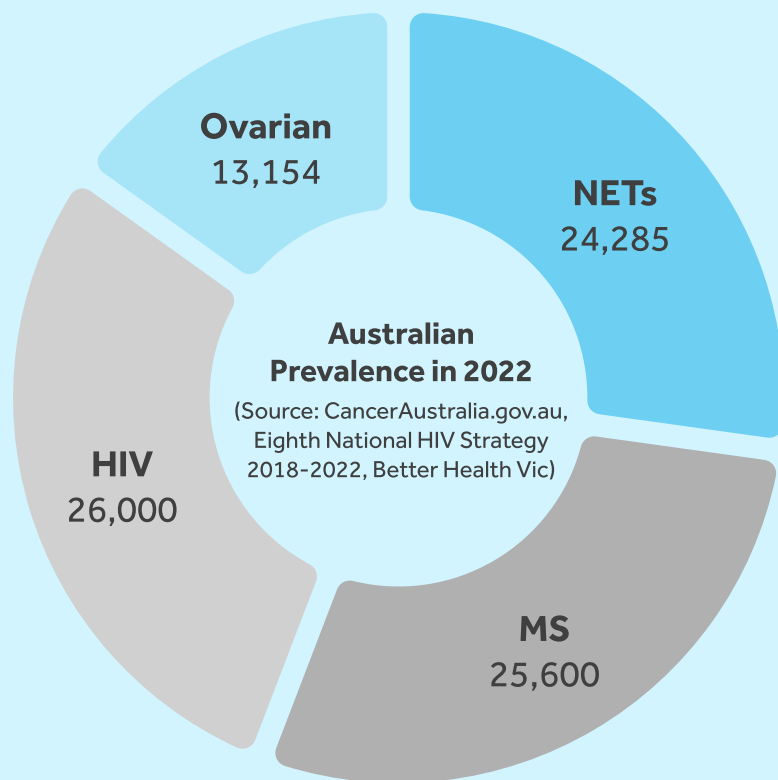


April 2023

NeuroEndocrine Cancer Australia receives the first ever Government Grant to increase awareness of NETs, increase awareness of Optimal Care Pathway and expand on patient resources.

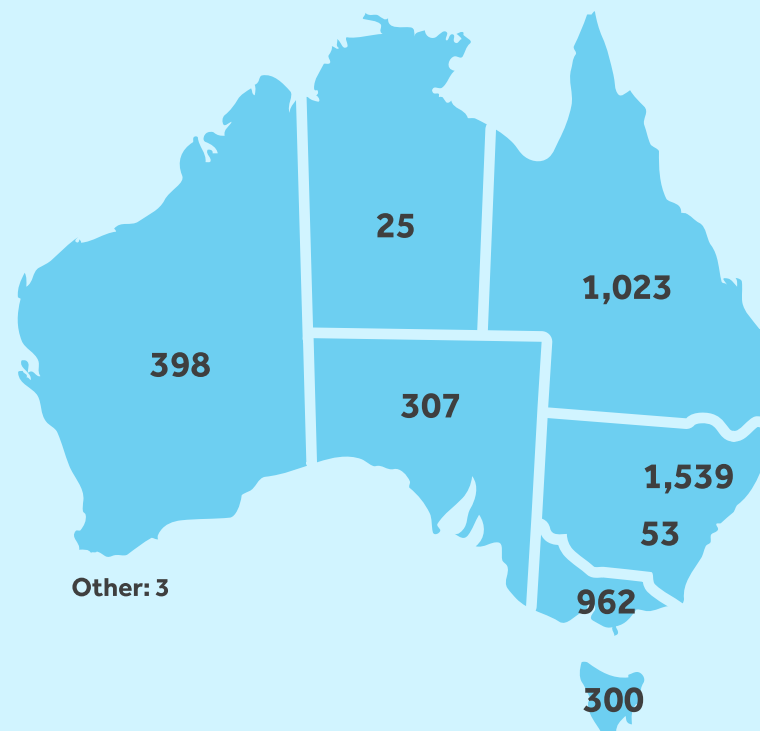
Neuroendocrine Tumours (NETs)-On the Rise

How many people are living with NETs?



Over 5,400+ patients are diagnosed with NETs each year

How many people are diagnosed annually?



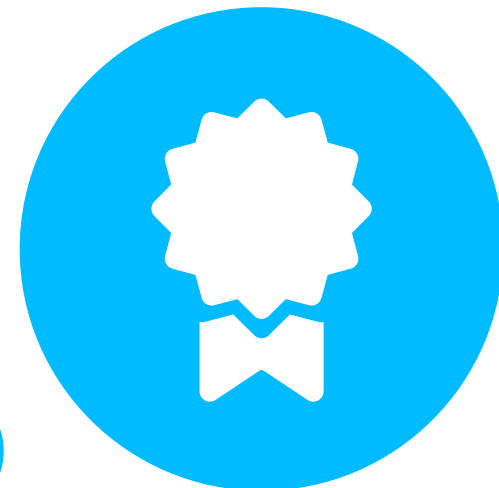
4,410 Australians newly diagnosed in 2018

(Source: Australian Institute of Health & Welfare)
Note: In 2022 this figure has increased by 23% to 5,437

Our 2022/2023 Impact

— (1/2)

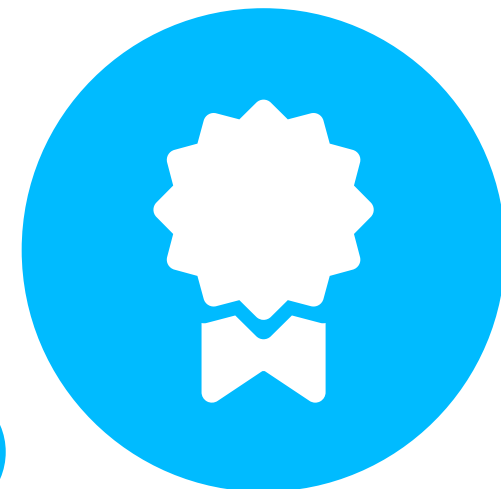
- Created and implemented virtual 4 week "Living with NETs" patient education workshops, these proved very popular and NECA now run 3 programs per year.
- Harnessed our data and created a NET Patient and HCP Heatmap so we can specifically target HCP Education in areas of need, and view where patient clusters are for best utilisation of in person support services (Patient forums, Support Groups etc).
- Met with MPs across the political landscape, alongside patients, to gain support of the Action Plan.
- Educated over 2,550 GPs and Nurses through online accredited modules.
- Continued to recruit to the national neuroendocrine tumour registry PLANET across the country.



Our 2022/2023 Impact

— (2/2)

- Refreshed the NECA Website to improve the user experience, making it easier for patients to find what they are looking for at every stage of their illness.
- NET Optimal Care Pathway launched 30 January 2023 – awareness campaign in progress and promotion of a quick reference guide to GPs.
- Delivered in-person and online education sessions to GP clinics, UTS Genetic Students, and Nurses to over 140 HCPs.
- AUSNET Study - in collaboration with Flinders University the AUSNET study is being trialed in Perth, Adelaide, Melbourne, Sydney, and Brisbane. The study is implementing a Nurse-enabled, shared-care model to address the unmet needs of people with Neuroendocrine Tumours. This will include GPs in the ongoing case management.



NET Nurse Support Highlights

Support highlights include:

- NET Nurse Support helpline – on average receiving over 180 contacts a month to 2200+ contacts a year.
- Refreshed support groups across Australia to meet demand, increasing National Zoom support groups and bought in guest speakers and worked with patients to organise media coverage to raise awareness where possible.
- The Private Facebook group continues to be a hub of activity, where shared experiences and peer support lifts spirits and soothes anxieties about up coming treatments (over 1700 active members).
- NECA remains the main referral service for NET patients around the country with referrals coming from Cancer Council, and all major hospitals and GPs.
- Expanded support hours, we welcomed a new NET Nurse to the fold, we now have two specialist part time NET Nurses who make up one full time equivalent. Our goal is to eventually have one NET Nurse for each state of Australia.



“Without equivocation, contact with our NET nurses changed and enhanced my interaction with and experience of this complex and challenging disease. Their presence is foundational to feeling, and being, supported during a time that is unpredictable, in a landscape that is very unfamiliar... their help to navigate all of this is INVALUABLE. From my heart, and my family's hearts, thank you for your excellent support and advocacy.”

—NET Patient

“Thank you to all the NET nurses—you all do an awesome job for patients living with Neuroendocrine Cancer. You show care, compassion and dedication. Keep up the great work.”

—NET Patient

Education Achievements



- Educated over 2550 Healthcare Professionals via our 10 online learning modules, earning them CPD points and valuable NET specific knowledge.

Podium Presentations and/or Posters delivered at:

- Clinical Oncology Society of Australia (COSA) 2023
- European Neuroendocrine Tumour Society (ENETs) 2023
- Australian New Zealand Society of Nuclear Medicine (ANZSNM) 2023
- Cancer Nurses Society of Australia (CNSA) 25th Annual Congress
- Held our first in person NET patient forum since COVID. We visited Brisbane, followed by Adelaide in June 2023

Awareness

Social Media • TV • Radio • Press

NECA had a bumper year communicating online:

- During the course of 22/23 we reached 60,000+ people via emails from our data base.
- Social media following grew to over 7,400 fans and followers, giving us the chance to educate, inspire and connect the NET community.
- Across the year we posted **over 1,000 times**.
- The private Facebook group is where patients and carers congregate to chat, vent and feel heard. This group of over 1,700 created an additional **100,000 interactions**.
- NET Cancer Day was focussed on reaching more Australians than ever this year and raising awareness, the campaign reached over **3 million Aussies**.



Watch Video



Advocacy Achievements

Multiple MP Meetings across all parties, meeting local and federal MPs. Subsequently many letters of support have been submitted to the Government from MPs. We continue to work hard to lobby in this space.

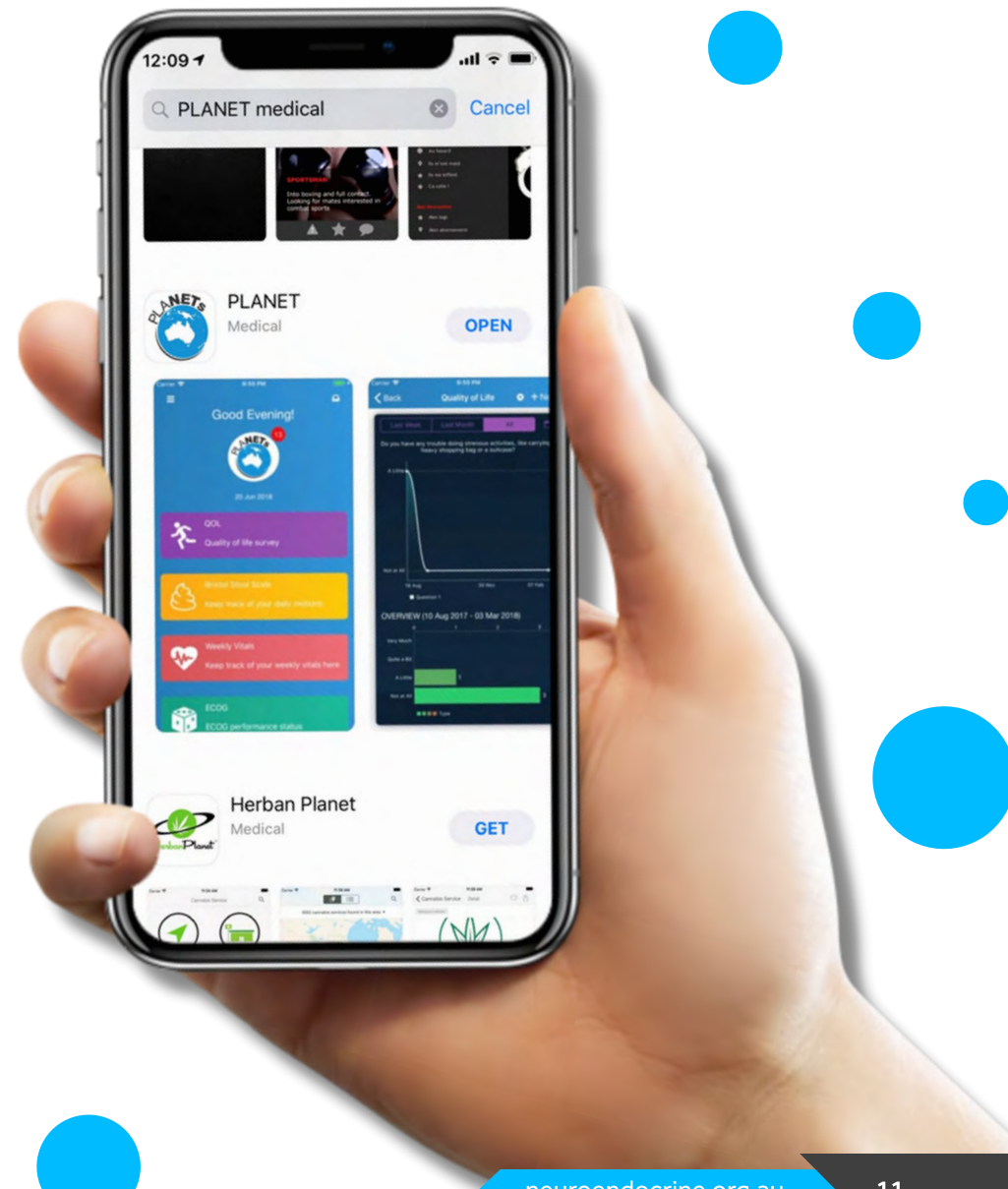
Some of our major advocacy achievements this year included:

- On going advocacy of the NET National Action Plan, MP meetings, Pharma meetings, educating patients
- Partial funding has been achieved for Action 2 and Action 4, celebrating our first ever major grant.
- Launched Optimal Care Pathway (OCP)
 - Promotion of this campaign is government funded for 2023/2024
- National Medicines policy
- Australian Cancer Plan
- HTA Review



Research

On going donations are truly appreciated to enable the continuation of the PLANET Registry and other NET-specific Research.





Our **Targets** in 2023/2024

We will continue to raise awareness of NETs, support patients and advocate for equitable care throughout 2023/2024 with a focus on:

- Expanding the NET Nurse Support Service, providing patients with essential support and guidance throughout their treatment journey.
- Raising awareness of the Optimal Care Pathway through out the healthcare community.
- Advocating for, and with, NET Patients for the Government to fund the 8 key asks of the National Action Plan.
- Expand patient resources, including explainer videos, NET patient forums and Living with NETs virtual workshops.
- Translate key explainer videos to be multilingual, helping a broader community of NET patients from non-English speaking backgrounds.
- Increase the reach of our Healthcare Professional Educational modules to educate as many nurses and GPs as possible, we aim to increase enrolments to over 3,000+.



Please help us help more NET patients, more often.

As we persist in our endeavors to secure Government funding for a NET Nurse in each state, it has become evident that our one (full-time equivalent) NET Nurse's workload is unsustainable.

It is crucial that we expand our team this year, no matter what it takes, so that we can provide assistance to a larger number of patients more frequently. We are confident that, with your generous support, we can make this dream a reality and enhance our capacity to serve the community.



Thank You!








You can rest easy in the knowledge that every dollar gifted to us, is spent on improving the lives of Australians living with NETs.

Thank you to our team, our board, our volunteers, our patient support facilitators, our consumer advisory group and our donors for being such a strong community in what has been a challenging year.

We thank you all for your incredible generosity, and look forward to continuing our partnership in the future.

Get in Touch

We would love to hear from you to answer any questions, or provide further detail.

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