

NeuroEndocrine Cancer Australia

Champions for early diagnosis and a cure

www.neuroendocrine.org.au

Donor Report

2021/2022



**NeuroEndocrine
Cancer Australia**

Champions for early diagnosis and a cure

Introduction

- Thank you for partnering with NeuroEndocrine Cancer Australia (NECA) as we champion for early diagnosis and a cure for neuroendocrine cancers.
- Our role, with your support, is vital to improving the lives of tens of thousands of neuroendocrine cancer patients and their families around Australia.
- NECA established in 2009, is the only Australian not-for-profit medical charity providing specialised support, advocacy and research for people living with Neuroendocrine Tumours (NETs).
- NeuroEndocrine Cancer Australia does not receive any government funding and relies on generous donors to provide NET patient care and support, funding of clinical trials and advancing NET research.



A word from our CEO

It is no surprise that the last couple of years have been more challenging than others. COVID restrictions made us as an organisation prioritise how we work in different ways, however at the forefront of our priorities was ensuring our patients and their families stayed safe and well, and continued to have access to their cancer treatments and appointments.

That makes the achievements of the last year even more exceptional and were the result of our hard working team and supporters.

The launch of the first National Action Plan for Neuroendocrine Tumours (NETs) - Preventing Australians from Slipping through the NET, was the culmination of years of research and real world lived experience that put forward 8 key actions we would like to see Federal and State governments support to ensure that NETs are recognised and resourced on equal footing with other cancers. Seeing patients and their families engaging with their local and federal MPs and talking through the issues and solutions was extraordinary and showed what we can do as a community.

In late 2021 NECA and the National Theranostics Roundtable Committee brought together stakeholders from around Australia to discuss – The Future of Precision Oncology in Nuclear Medicine. This was the first meeting to bring all stakeholders together and the recently released report summarises the many aspects presented at the event required for this precision medicine, hearing from researchers, clinicians, industry and from the Chairs of the MSAC, TGA and Cancer Australia.

Whilst these were our big advocacy pieces our main role in supporting patients is at the heart of what we do and this saw our NET nurse specialist service see a 25% increase in demand which was a 20% increase from the year before. With one nurse supporting potentially 22,000 Australians living with NETs, we have more than reached capacity. That is why we are making it a priority to reach out to the new Federal Government to give NETs a fair go and provide us with a NET nurse per state.

Whilst we might be small our achievements are large, and we could not do this without your generous support. You can rest assured that every dollar donated to NECA is stretched to its last cent and our small wins are your wins.

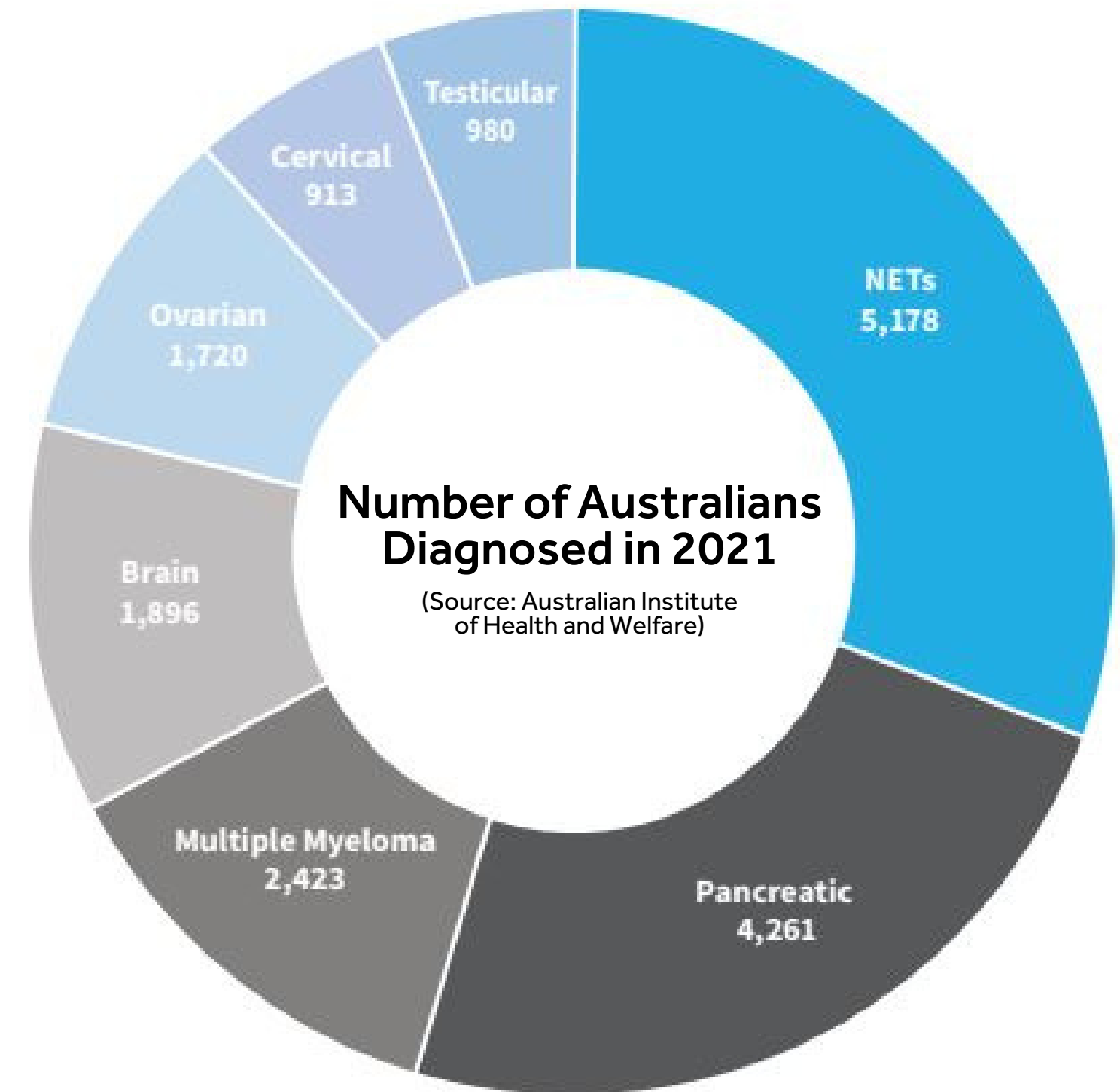
Here is to another big year ahead!



Simone Leyden
CEO & Co-founder

How many Australian's are diagnosed with Neuroendocrine Tumours (NETs)?

- The incidence of NETs is on the rise and is estimated to affect 15/100,000 Australians (approx. 5,178 cases diagnosed in 2021) more than brain, ovarian, testicular, cervical, multiple myeloma, and pancreatic.
- 5 year survival for all NETs is 48% compared to a survival rate of 95% for breast cancer.
- Correct diagnosis can take on average 5-7 years due to lack of awareness.
- Once a person is finally diagnosed, in over 50% of cases the cancer has spread to secondary organs, making a cure through surgery less likely.



Did You Know?

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7th
most
diagnosed
cancer

It is estimated Neuroendocrine Cancer will be the 7th most diagnosed cancer in 2021



22,000+

Australians living with Neuroendocrine Cancer



5,100+

Australians are diagnosed annually



1 Australian is diagnosed with a Neuroendocrine Tumour every 2 hours

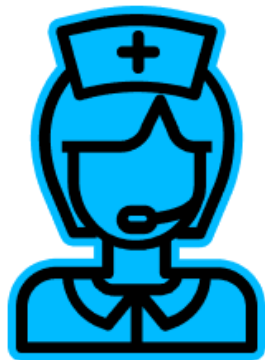
1 in 2

patients report being originally diagnosed with something else

Our **Five Pillars**

Our foundation is directed by five pillars: patient support, research, education, awareness and advocacy.

These pillars have been created to give neuroendocrine cancer patients, their families and friends, a voice in the community and access to the care and treatment that they deserve.



SUPPORT



EDUCATION



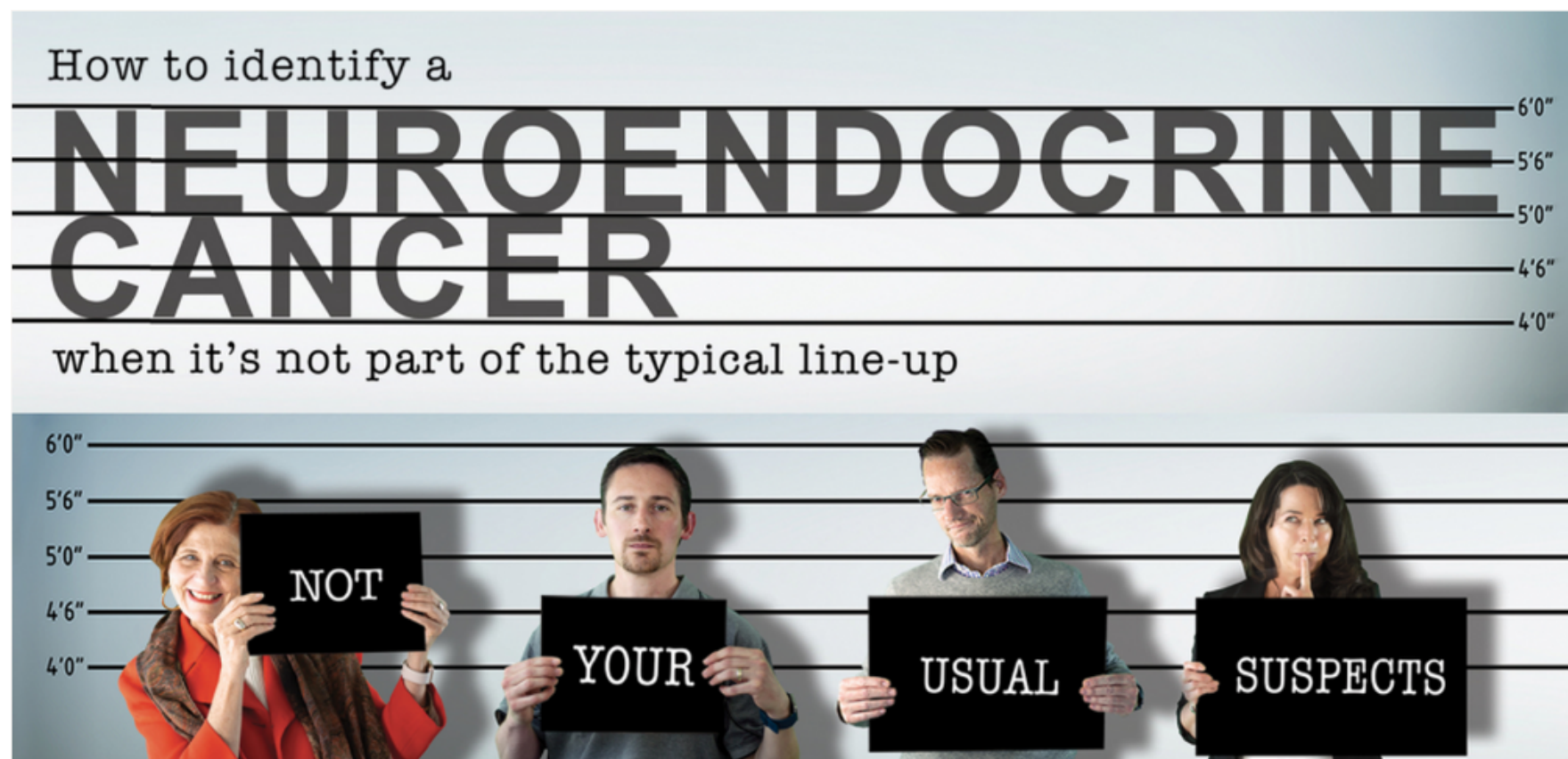
RESEARCH



AWARENESS



ADVOCACY



Our Achievements in 2021/2022

Key highlights:

21/22 has been a bumper year for NeuroEndocrine Cancer Australia:

- Development of the first National NET Awareness and Action Plan 2022-2027 - "Preventing Australians from Slipping Through the NET", launched virtually on November 10, 2021
- Meeting with MPs across the political landscape to gain support of the Action Plan
- Convened first National Theranostics round table on October 28, 2021
- Developed two new explainer NET specific infographic videos
- Collaborated with Cancer Australia and Cancer Council Vic to write the first national Optimal Care Pathway to be officially launched second half 2022
- Collaborated with Cancer Council Vic to develop and launch the first NET patient education program.
- Educated over 1500 GPs and Nurses through online accredited modules
- Continued to recruit to the national neuroendocrine tumour registry PLANET across the country.



SUPPORT Achievements

Support highlights include:

- NET Nurse Support helpline – on average receiving over 180 contacts a month, this number has been increasing by 25% a year.
- Support groups across Australia – over 90 face to face groups around the country. In response to COVID-19 all support groups were moved to online zoom format. COVID permitting, these have all been migrated back to face-to-face, with our Project Manager ensuring the COVID plans were implemented for each market.
- Private Facebook groups (over 1600 active members).
- NECA remains the main referral service for NET patients around the country with referrals coming from Cancer Council 131120 and all major hospitals and GPs.

20%

NET Nurse phone line has increased an additional 20% this financial year. Post January we are seeing an additional 10% increase in activity.





RESEARCH Achievements

- Research highlights include:
 - CONTROL NET's clinical trial has now finished recruiting patients and is in follow up stage. Results from the trial have been positive and presented at national and international medical conferences including the American Society of Clinical Oncology (provided on request).
 - NECA is Associate Investigator on the Medical Research Future Fund grant - AUSNET- in the development of NET specialist nurse and GP shared care pathways.
 - PLANET Registry and PROMS app is actively recruiting at Royal North Shore Hospital, Royal Brisbane and Womens Hospital, Peter MacCallum Cancer Centre, Queen Elizabeth and Fiona Stanley Hospitals. There are now over 2,300 NET patients in the registry. This year we have opened more sites including Genesiscare Frenchs Forest, with the Austin and Boxhill hospitals to come online soon.

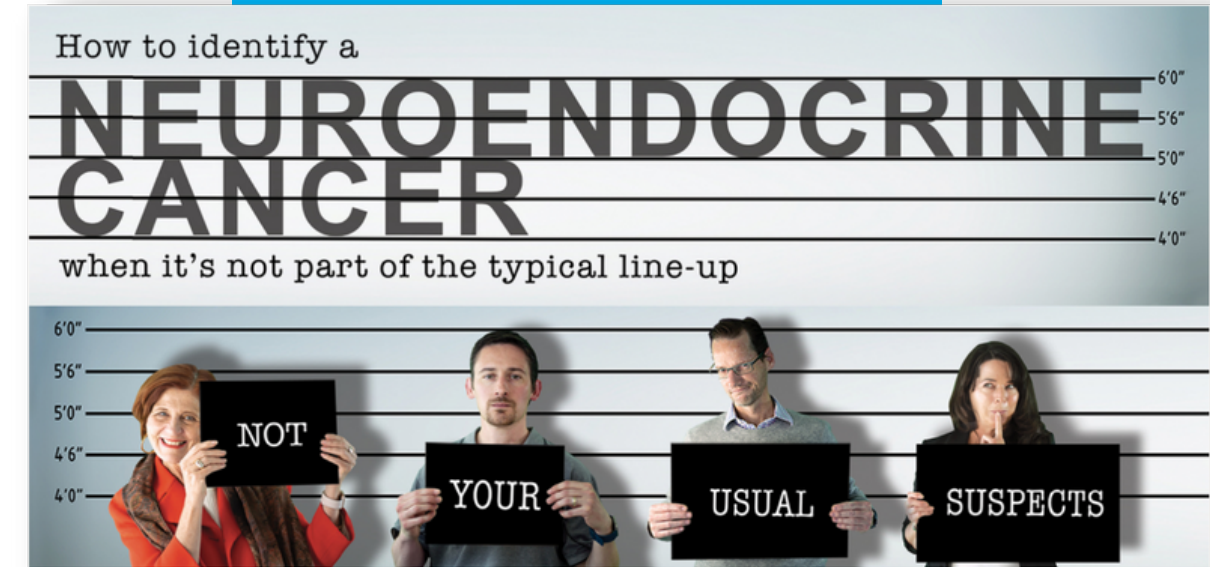




(1/2) EDUCATION Achievements

- Within its first year of launch GP Category 1 (40 CPD) and Australian College of Nurses (10CPD) online education course has doubled the industry average for HCPs starting the course over the 18 month period.
- To date over 1500 Healthcare Professionals comprising GPs and Nurses, have enrolled.
- Whilst we endeavour to secure Government funding for a much need promotional campaign for Healthcare Professions, we are asking our NET community, including patients and carers, to download an educational promotional flyer and take to their local healthcare professionals.
- Our website has been upgraded so Healthcare Professionals can book "in-services" online. Our NET Nurse has performed In Service training from Esperance to Ipswich and many places in between. Over 230 Nurses received free training in this financial year.

3 Education of healthcare professionals (HCPs)





(2/2)
EDUCATION
Achievements

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- Chaired Australia's first national round table on Theranostics. The Future of Precision Oncology in Nuclear Medicine was held on 28th October 2021
- Partnered with Peter MacCallum Cancer Centre to host a celebration of the 25th Anniversary of PRRT at Peter MacCallum Cancer Centre
- Publications and posters presented at:
 - Clinical Oncology Society of Australia (COSA) 2022
 - European Neuroendocrine Tumour Society (ENETS) 2022
 - Australian New Zealand Society of Nuclear Medicine (ANZSNM) 2022
 - Cancer Nurses Society of Australia (CNSA) 24th Annual Congress
- BioPhramaDispatch2022





(1/3)
AWARENESS
Achievements/ Media

World NET Cancer day proved to be the ideal time to launch the National Action Plan.

TV Coverage:
Nightly News 7 Tasmania



Print & Online Coverage

There was extensive pick up of the Australian Associated Press coverage of the story across metropolitan, regional and online news publications. 16 different Australian outlets ran the Little known, complex cancer on the rise story, along with one New Zealand outlet and one Australian.

National Radio Coverage

"Neuroendocrine Cancer is on the rise" News story and interview with Simone ran on Australian Radio Network News segments nationally (KIIS Network, Pure Gold and The Edge) and also reported on 2CC and 2CA in Canberra.

Medical Specialist News

We reached HealthCare Professionals via The Limbic Endocrinology eNews and The Limbic Oncology eNews.

Med News - MedTvos:

The well respected Med News ran an interview with our very own Simone Leyden and Professor Rod Hicks.

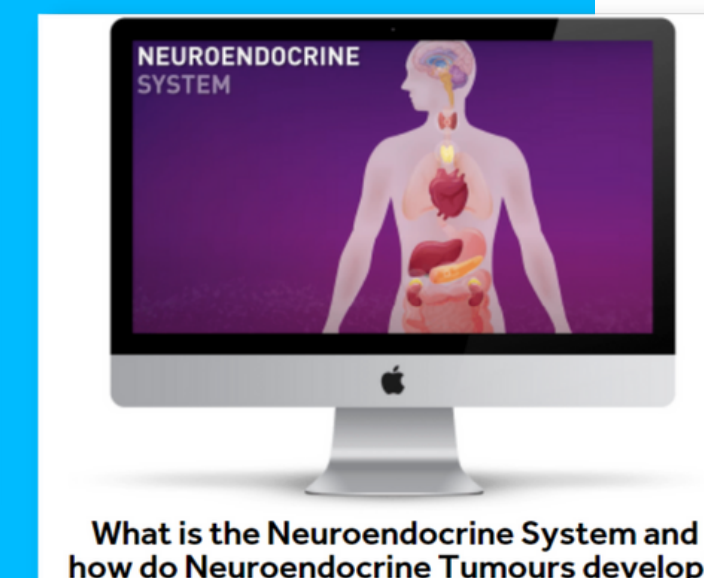
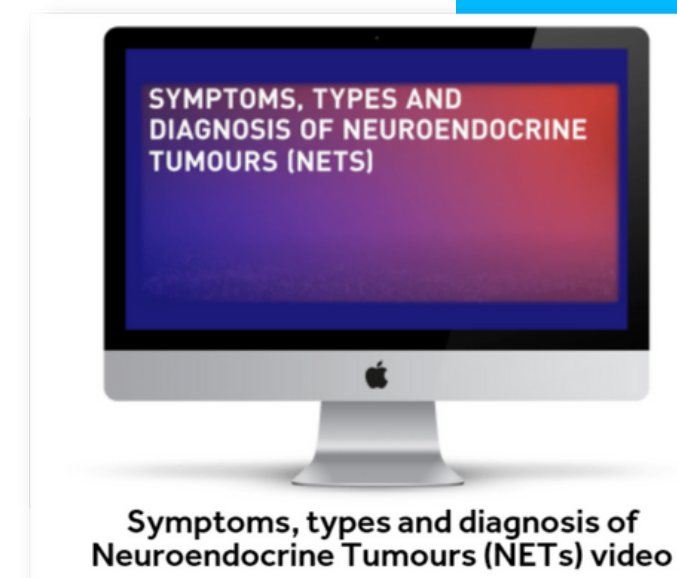
Oncology News - Theranostics and NETs: Where do we go next? - Podcast





(2/3)
AWARENESS
Assets & Partnerships

- Launch of two new explainer videos.
 - What is the Neuroendocrine System and how do Neuroendocrine Tumours develop?
 - Symptoms, types and diagnosis of Neuroendocrine Tumours.
- Launched the first ever NeuroEndocrine Cancer Australia overview video to assist patients in understanding how NECA are helping across all facets of care.
- Partnered with two pharmaceutical companies and participated in two national campaigns encouraging all Australians to go to the Doctor and #GetChecked:
 - New Normal, Same Cancer, AstraZeneca campaign
 - Wellness Day, Ipsen





(3/3)
AWARENESS
Social activity

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NECA had a bumper year communicating online:

- During the course of 21/22 we reached 87,000+ people via emails from our data base
- Over 18,000+ people commented/liked and shared our Social Media posts
- Social media following grew to over 6,600 people representing a 10% increase
- Across the year we posted 720 times, with a huge 16,100 engagements. This tells us our community sees us a source of relevant, credible information.
- The private Facebook group is where patients and carers congregate to chat, vent and feel heard. With an additional 1,200 posts that garnered 45,259 reactions.

1,920 Posts → **61,359 Engagements**



22,000+
Australians living with
Neuroendocrine Cancer

7th
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cancer

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1 in 2

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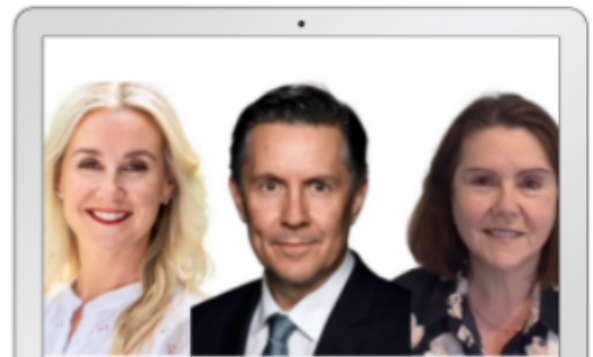
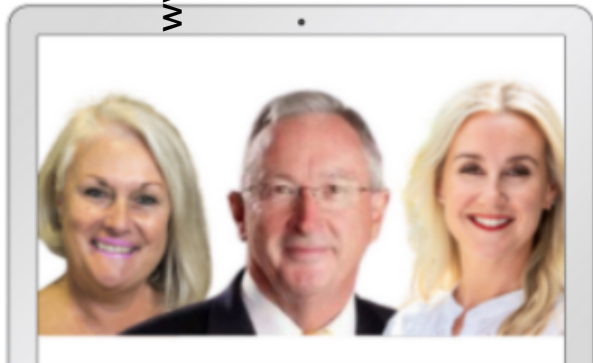
ADVOCACY

Achievements

Development of National Action Plan, giving our community the focus and tools to advocate for themselves and each other.

- Meetings with MPs from all over Australia.
- Dedicated web page to arm our community with information, the latest facts and scripts so they feel comfortable meeting with MPs.
- Development of Optimal Care Pathway (OCP)
 - Our Project Officer was seconded to Cancer Council Vic to collaborate and guide the writing of the Optimal Care Pathway
 - This OCP will raise awareness with HCPs and the general public and assist in improving referral pathways for NET Patients
- Theranostics Roundtable. The Future of Precision Oncology in Nuclear Medicine
 - Convened Australia's first round table to discuss the current state of play and future opportunities for theranostics in Australia. Co-ordination of all stakeholders including Government and Private enterprise as integral to the success of the all day forum. With 35 speakers and 255 attendees the outcomes published in the Theranostics Roundtable report

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Our **Targets** in 2022/2023

Despite currently receiving no government funding, we have some very ambitious objectives for 2022/2023:

- Optimal Care Pathway roll out and support
- Expanding the NET Nurse Support Service with an additional nurse and developing a framework to include Oncology Social Workers
- Advocating to pilot the agreed Federal and State Government Innovative Model of Care framework into NETs
- Expand and fund the PLANET registry and aim for its first study across all sites
- Increase awareness about the ACN and RACGP online modules to educate as many nurses and GPs as possible

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.



Our Team

www.neuroendocrine.org.au



Simone Leyden
CEO & Co-founder



Meredith Cummins
Project Officer



Joyce Bonello
NET Nurse



Adie Williams
Marketing &
Partnerships Manager

Without you, we can't do this. With you, we can.

Get in Touch

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



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