



**INCA Full Members**

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- A.I.NET, *Italy*
- AMEND, *UK*
- APOZ, *Bulgaria*
- APTED, *France*
- Carcinoid Cancer Foundation, *USA*
- CarciNor, *Norway*
- CARPA, *Sweden*
- CNETS, *Canada*
- CNETS, *Singapore*
- NET Patient Foundation, *UK*
- NET Research Foundation, *USA*
- Netzwerk Neuroendokrine Tumoren, *Germany*
- Netpa, *Denmark*
- PanCAN Japan, *Japan*
- Pheo Paratroopers, *USA*
- The Unicorn Foundation, *Australia*
- The Unicorn Foundation, *New Zealand*
- VZW NET & MEN Kanker, *Belgium*

For more information:



**The Global Voice  
for NET Patients**

## Uniting NET groups from around the world

The International Neuroendocrine Cancer Alliance (INCA) has committed to being the **global voice** for neuroendocrine cancer patients. Envisioning a world where all neuroendocrine cancer patients get a timely diagnosis, the best care and ultimately a cure, INCA's core mission is to **raise awareness** of neuroendocrine cancers, **advance NET research** and **strengthen NET patient groups globally**.

The Alliance currently has **18 Full Members** – NET patient advocacy organizations from **Asia, Australia, Europe, and North America**.

*“It is the passion to change things for the betterment of neuroendocrine cancer patients that drives us forward as a deeply committed team, to unite patient advocates from around the globe in this effort.”*

**INCA Team**



## Empowering patients

Encouraging early diagnosis by working collaboratively with the healthcare community and the public, the Alliance also recognizes universal access to high-quality **multidisciplinary care** and the dissemination of accurate and user-friendly information about neuroendocrine cancer as its top priorities.

INCA serves as a global platform to support existing and new patient-focused neuroendocrine groups and advocacy organizations from around the world. By maximizing the capacity of its current members and actively reaching out to new ones, INCA encourages sharing **best practices** and experience, which is crucial in the context of rare cancers.

As a network of patient advocacy organizations, INCA is a **resource for NET patients**, especially newly diagnosed patients, to find support groups in their countries and access other patients “on the journey”. Informed patients are better collaborators, since they can be active participants in the disease management process.

## Facilitating global action

In its capacity of a **global patient-driven** organization whose core mission is raising awareness, INCA works towards providing more attention for the rare disease space, supporting policies that improve research funding, insurance coverage, etc.

**November 10** has been promoted as Worldwide NET Cancer Awareness Day, to secure a greater voice for NET patients by joining efforts globally to engage people in various awareness-raising and educational activities.

**The results of the first-ever global NET patient survey** to quantify NET patient experience – a collaborative effort between INCA and Novartis, were captured in a number of abstracts, posters, and oral presentations, which were presented at over 15 medical meetings and published in medical journals. The goal of the survey, which was completed by nearly **2,000 patients** from **12 countries**, was to increase understanding of the experiences, needs and challenges of NET patients, and provide insights and learnings between countries and regions to **advance NET care** on a global level. The first global NET patient survey showed a substantial NET-related burden and identified areas for improvement to enhance patient care.