

INCA – the Global Voice for NET Patients

The International Neuroendocrine Cancer Alliance (**INCA**) is the global voice in support of patients with neuroendocrine cancer and genetic neuroendocrine tumors (NETs) and their carers with a mission to:

- ✓ raise awareness about all types of NETs;
- ✓ push for scientific advancements with a focus on identified unmet needs;
- ✓ provide a platform for global collaboration to address the many challenges NET patients and the medical community face, in securing a timely diagnosis and accessing optimal treatment, support and care.

The alliance's work is driven by the vision of a world where all patients with neuroendocrine cancer and genetic neuroendocrine tumors (NETs) get a timely diagnosis, optimal treatment, support and care and ultimately a cure.

INCA is an umbrella organization representing 26 patient advocacy and research groups from 6 continents. A key priority in **INCA**'s work is creating common platforms and working in collaboration with medical communities to fulfill the informational needs of patients, ensure access to the highest standards of care and facilitate patient involvement in research.

INCA has focused its efforts on identifying and addressing the unmet needs of the NET patient community in an attempt to improve the lives of all those affected by this complex disease, no matter where in the world they live. True to the principle of evidence-based advocacy, **INCA** has championed a number of international surveys to assess the unmet needs in the management of NETs from the key stakeholders' perspectives. The results of this patient-generated research have been presented at all major oncology and NET-specific conferences over the last few years, notably winning best poster awards at the ESMO Congress 2018 and at the ENETS Conference 2019. An article summarizing the findings of a recent survey was published as an open-access manuscript in the International Journal of Cancer, which was in turn recognized as one of the top downloaded papers for the 2018-2019 period.

INCA works to facilitate consensus among the key players on the potential barriers to improving patient outcomes and research strategies to advance research in the interest of patients.

INCA believes that only collaborative efforts can drive change, so the organization has developed strategic partnerships with the NET medical societies around the world, as well as across the wider cancer advocacy and rare disease community.

INCA has recognized gathering robust evidence as key priority along with informing and educating all those involved in the care of neuroendocrine cancer patients in order to make change happen for all NET patients around the world.