

Improving understanding of neuroendocrine tumors (NETs) – a key to improving patient outcomes

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Background:

- The International Neuroendocrine Cancer Alliance (INCA) is a global umbrella organization advocating on behalf of neuroendocrine patients to improve time to diagnosis, care and research.
- The global INCA Survey of Challenges in Access to Diagnostics and Treatment for NET Patients (SCAN) confirmed that early diagnosis is a major challenge globally, with average time to diagnosis of over 5 years and almost half of patients with stage IV disease.

Aims:

Raising awareness of the impacts of delayed diagnosis and misdiagnoses in neuroendocrine tumors (NETs) is a key focus for INCA and the global neuroendocrine cancer community.



Methods:

To focus on reducing time to diagnosis, INCA launched 2 campaigns:

- a concerted communication effort around late diagnosis and misdiagnosis among patients, carers, healthcare professionals and the general public: Neuroendocrine Cancer Day campaign 'Know the symptoms. Push for diagnosis' with global scope and in 10 languages

Conclusions

Collaboration among all key stakeholders involved in the diagnostic pathway, ongoing education and awareness are vital components to mitigate the challenges around delayed diagnosis.



Methods (continued):

- The campaign ran across Facebook, Twitter, Instagram and Google Ads
- an online educational program targeting primary healthcare professionals (HCPs) to address key aspects of diagnosing and managing NETs

Results:

- The awareness campaign message was supported by all INCA members and partners and reached 20,334,765 people via social media.
- Patient stories from around the world played a crucial role in profiling the key challenges in early detection and changing attitudes.

Future Directions for Research:

- It was determined that general practitioners are heavily involved in both the diagnostic and ongoing treatment pathway for patients, yet awareness of the signs and symptoms of NETs in this cohort of HCPs is lacking.
- INCA will address this via CME-accredited online courses comprised of self-driven modules with associated tests and webinars.