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NET Cancer Day: Make the world talk about earlier diagnosis of neuroendocrine cancer

November 10 is NET Cancer Day, an annual event created by the International Neuroendocrine Cancer Alliance (INCA) (and supported by (INSERT MEMBER ORGANIZATION NAME)) that aims to raise awareness of neuroendocrine tumors (NETs) around the world.

On this day thousands of NET patients, their families and supporters, and NET medical specialists from around the globe come together on social media using the hashtag #LetsTalkAboutNETs, to help **raise awareness around this often-misdiagnosed and forgotten cancer**, and change attitudes to neuroendocrine cancer in order to secure optimal diagnostic pathways for NET patients, no matter where they live.

The results from the Survey of Challenges in Access to Diagnostics, Treatments and Care for NET Patients (SCAN), a global survey conducted by INCA, show that almost half of NET patients had stage IV disease at the time of diagnosis, meaning that their cancer had spread to other organs. Mean time to diagnosis was 5 years, lower in Asia and higher in North America (Europe – 4.05 year vs. North America – 6.44 years vs. Asia – 2.28 vs. Oceania – 4.81 years). Four out of five misdiagnosed patients globally (81%) failed to receive a correct diagnosis within 1 year (North America (86%); Oceania (82%); Europe (80%); Asia (72%).

INCA President, Catherine Bouvier, says, *“SCAN has confirmed facts that advocacy organizations have been highlighting for many years, and that we **now** have to address. Equitable access to innovative diagnostic and treatment tools in neuroendocrine cancers and genetic NETs is a significant global challenge, and a focused effort should be directed at advocating to include these cancers and tumors in national cancer plans, but also to significantly increase awareness and provide specialized education amongst all relevant HCPs, to facilitate faster detection, diagnosis and referral to expertise. We need to change attitudes towards rarer cancers and ensure all affected have a clear, effective and holistic diagnostic/treatment pathway.”*

Executive Director of INCA, Teodora Kolarova continues, *“The high level of misdiagnoses reported in the SCAN results really highlights insufficient knowledge about NETs amongst medical communities. NET patients need access to earlier diagnosis and improved symptoms awareness – NET Cancer Day is about speaking up to make change happen.”*

Affecting 7 in every 100,000 people around the world, NETs are defined as a less common cancer, with incidence similar to that of brain tumors, thyroid cancers, liver cancers, pancreatic cancers and kidney cancer, yet awareness amongst the medical community and general public is still relatively low. Healthcare professionals at all levels of care should be equipped with the skills to identify neuroendocrine cancer symptoms and perform or refer for appropriate diagnostic tests at the right time.



As awareness is key to changing the above statistics, this year INCA has asked the global NET patient community to speak up and share their route to NET diagnosis stories. On the very day – November 10th, a video carousel of NET patients’ selfies from around the world, capturing their experience with diagnosing NETs, will be launched.

Neuroendocrine Tumor (NETs) Facts and Stats*

- 7 out of every 100,000 people globally are diagnosed with NETs each year
- NETs affect men and women of all ages, including children
- NET symptoms can often be non-specific but can include: weight loss, dry, hot flushes, shortness of breath, asthma-like symptoms, fatigue, pain, bloating and diarrhea
- Symptoms are often similar to more common conditions: IBS, asthma and anxiety, therefore the risk of misdiagnosis is high
- According to preliminary SCAN results, 53% of NET patients have secondary growths at diagnosis
- According to preliminary SCAN results, 44% of NET patients are misdiagnosed
- NETs can arise throughout the body in organs that contain neuroendocrine cells such as, stomach, bowel, lungs and pancreas
- NETs – “if you don’t suspect it you can’t detect it” – awareness and education is the key

***For more information on neuroendocrine tumors (including supporting stats) or to access the 2020 campaign toolkit head to: <https://incalliance.org/net-cancer-day-toolkit-2020/>**

Follow NET Cancer Day activities via INCA’s social media accounts:

Facebook: @netcancerday
Twitter: @netcancerday
Instagram: @netcancerday

Background Information:

International Neuroendocrine Cancer Alliance (INCA) – the home of NET Cancer Day is the global voice in support of patients with neuroendocrine cancer and multiple endocrine neoplasia syndromes.

INCA’s mission is to raise awareness about all types of NETs; push for scientific advancements with a focus on identified unmet needs; and to 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.

INCA represents 26 patient advocacy organisations from 22 countries around the globe.



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