

# Think NENs Global Educational Program on Neuroendocrine Neoplasms

## Diagnostics and Management for Primary Care Physicians

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### INTRODUCTION

Neuroendocrine neoplasms (NENs) are complex neoplasms with increasing incidence and prevalence worldwide that can originate in various organs, but most commonly in the gastrointestinal tract and the respiratory system.

2359 NEN patients/carers and 436 HCPs from 68 countries participated in the Survey of Challenges in Access to Diagnostics and Treatment for NET Patients (SCAN), designed and carried out by the International Neuroendocrine Cancer Alliance (INCA) in 2019. Mean time to NEN diagnosis was 5 years [N=1042]. Almost half of patients (46% [1077/2359]) were diagnosed with stage IV NENs at time of diagnosis.

SCAN results spotlighted the important role primary care physicians (PCPs) play in NENs detection and care – 19% (456/2359) of the HCPs who suggested the diagnostic test, and 44% (953/2359) of the HCPs actively involved in the ongoing monitoring of NEN patients were PCPs, according to patients.

To help primary care physicians (PCPs) detect and manage neuroendocrine cancer in their practice, INCA has championed a global educational initiative. INCA is the global voice in support of patients with neuroendocrine tumors (NETs) and genetic syndromes (Gen NETs). INCA represents 37 patient advocacy and research groups from 29 countries, across 6 continents.



### OBJECTIVE

The ultimate objective of Think NENs Educational Program for Primary Care Physicians is to increase awareness, to make PCPs think about NENs and to provide the latest knowledge and skills in detecting and managing NENs in primary care, including referral pathways, as a means to achieve timely disease diagnosis, optimal treatment and care, and better patient outcomes.

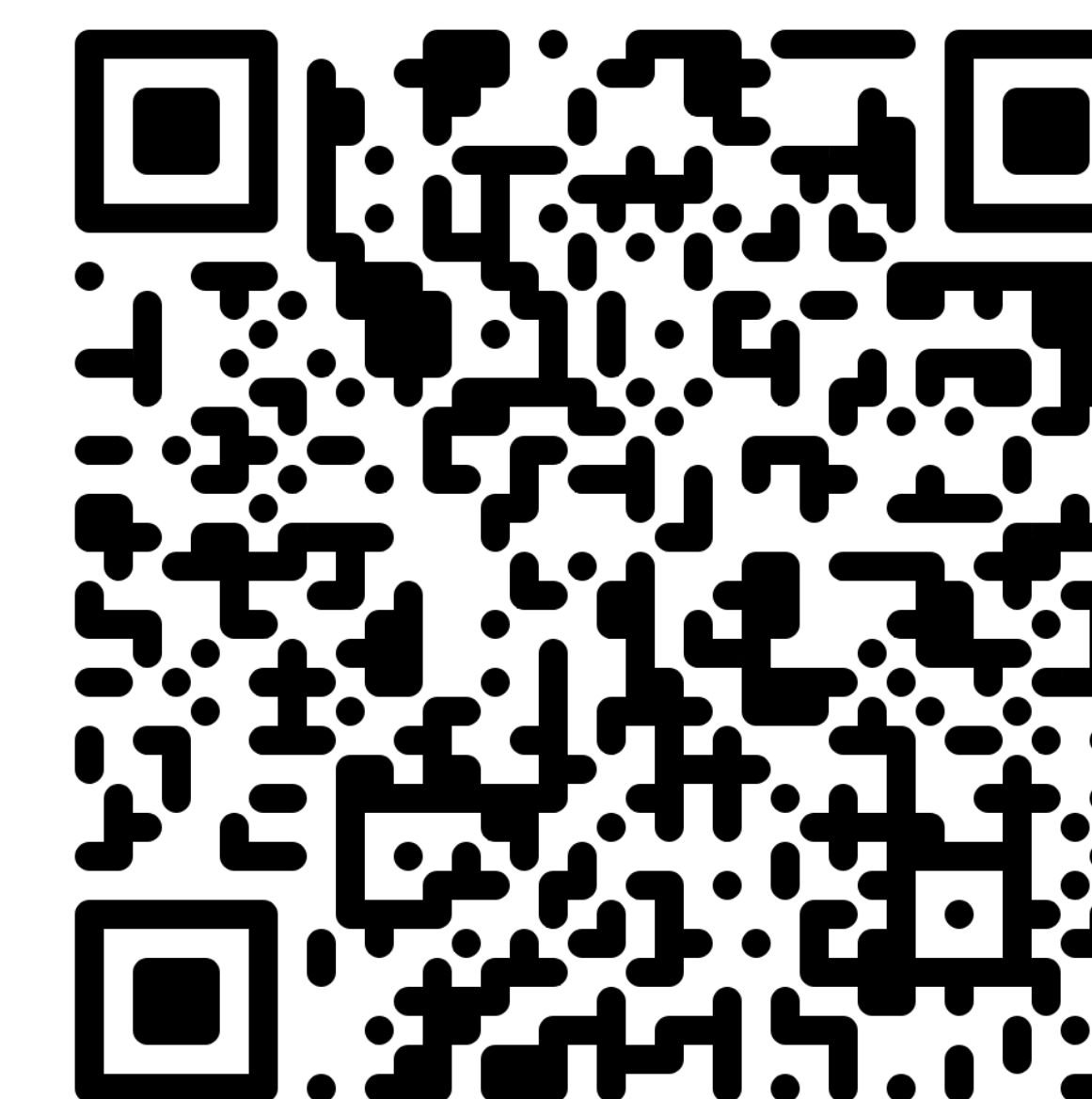
**The educational program aims to facilitate:**

- ✓ Early detection of NENs in patients with recurrent or persistent symptoms
- ✓ Management of common side effects of treatments and issues of the NEN patient journey
- ✓ Searching for NEN expertise globally

The content has been elaborated by a scientific committee representing patients with NEN (an international panel from INCA), NEN experts from around the world (from ENETS, NANETS and CommNETs) and PCPs from Turkey, South Africa, and United Kingdom, as well as an emergency physician from the United States.

### METHODS

A team of medical experts in NENs, PCPs and patient advocates from across the globe developed Think NENs Global Educational Program. The free online training includes everything PCPs need to know about diagnostics, treatment and care of patients with NENs. The faculty comprises esteemed NEN experts from around the world, as well as primary care physicians, an emergency medicine physician and a psychotherapist specialized in working with the rare disease community. All content is video-based, including a series of interviews led by PCPs and brief expert talks.



### RESULTS

Think NENs Global Educational Program for PCPs includes 1 main module of 3 videos providing concise knowledge about neuroendocrine cancer diagnosis and managing patients via Q&A sessions between PCPs and neuroendocrine neoplasm (NEN) experts from around the world, as well as 13 supplementary videos on common NEN types, the impact of treatments and genetic NENs. Upon successful completion of exam, the main module can provide 1 UEMS-EACCME® credit, which has an agreement of mutual recognition of credits with the American Medical Association. The program provides heightened diagnostic awareness and skills to evaluate the common diagnostic pitfalls in the most frequent type of clinical diagnostic scenarios in primary care. It also maps the common NEN treatments and their implications that can be seen in primary care, as well as ways to deal with them.

The program is available in English, French, German, Italian, Portuguese and Spanish.



### RESULTS [cont.]

This course design is unique because it was specially created with the family doctors' point of view in mind. The content is guided by primary care physicians from different parts of the world who pose their questions to prominent NEN specialists in order to shape the basic NEN knowledge framework from the perspective of the primary care.

- ✓ Bite-size information
- ✓ Key take-aways in 6 languages
- ✓ Transcripts in 6 languages
- ✓ Support expert network and supplementary resources available

### CONCLUSION

- Delayed NEN diagnosis and suboptimal patient care are enduring global challenges.
- PCPs play a key role in NEN diagnostics and ongoing patient monitoring.
- Improved understanding of NENs among PCPs is of instrumental importance for improving patient diagnostic and care pathways, as well as patient outcomes.
- Continuous educational efforts should be employed to support PCPs in their practice.

### REFERENCES

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