



# Launch event of NENs Policy Recommendations

## SYNTHESIS REPORT

(28 September 2022 (12-13 CET))

### 1. Introduction.

The EU Launch event of the EU NENs Policy Recommendations was held on 28 September 2022 with the participation of some of the NENs Policy Recommendations authors, experts and policy makers:

**Professor Marianne Pavel** (Chair of Endocrinology at Friedrich-Alexander University of Erlangen, Vice-chair of ENETS, NENs recommendations author);

**Prof. Catherine Bouvier Ellis** (CEO & Co-Founder NCUK, Board Member INCA, NENs recommendations author));

**Prof. Jean-Yves Blay** (Centre Léon Bérard, the Comprehensive Cancer Centre of Lyon, ERN-EURACAN Coordinator, NENs recommendations author);

**Prof. Rocio Garcia-Carbonero** (Hospital Universitario 12 de Octubre, NENs recommendations author));

**Prof. Paolo G. Casali** (Fondazione IRCCS Istituto Nazionale Tumori, Milan);

**Nicolas Gonzalez Casares** (Member of the European Parliament (S&D);

**Dr. Jose A. Valverde** (Policy Officer at DG SANTE - Unit B.3 - European Reference Networks and Digital Health).

The event was facilitated by RPP Group and sponsored by AAA.



### 3. The road to personalized medicine: a challenge for patients.

It was noted that the same increased knowledge and understanding in respect to classification, pathogenesis, treatment and research regarding NENs that has led to many developments in these years, at the same time **highlighted the significant challenges that NENs patients face when seeking for personalized healthcare** (from the sense of being unheard, to being surrounded by the unfamiliar, especially in regard to terminology, diagnostics and treatments, coping with significant uncertainty). **Vast inequalities** remain in the set up and delivery of care which **requires strong legislative support**. It was therefore stressed the strong potential that these updated NENs Policy Recommendations hold **to provide guidance to the work of the EU**.



### 4. The example of ERN-EURACAN and the lack of structured referral pathways at national level.

The support of the European Commission for this work was generally considered key particularly to address the issues of the **lack of structured referral pathways at national level in many European countries and the national dimension of integration of European networks** for which the document provides a specific table. The European Reference Network [EURACAN](#) dedicated to rare adult solid tumors (which includes 106 centers from 26 countries gathering experts from 10 different domains **including a specific domain on NENs**) was mentioned as a best practice and **as the cement to hold together other expert reference programmes in the field of rare cancers**. Finally, it was underlined the importance of **raising awareness and mobilization of the single patient's community** (here the case of NENs was once more mentioned as a best practice) and of **funding networking activities**.

### 5. A perspective from policy makers.

It was noted that the EU has recently taken bold decisions in the field of cancer and rare diseases and that the COVID-19 pandemic gave a further push to health reforms in general, including these related to cancer and rare diseases. **The experience of the [Report on strengthening Europe in the fight against cancer-towards a comprehensive and coordinated strategy report](#)** was mentioned for this purpose and more initiatives are upcoming in the next months (see the revision of pharmaceutical legislation, the revision of the legislation on medicines for children and rare diseases and the legislative proposal on the European Health Data Space (EHDS)).

The same is happening at European Commission level where 24 ERNs are in place (with at least 4 of them dealing with rare cancers) and some important initiatives are in an advanced preparation stage, among which a **Joint Action on integration of ERNs into national health systems** (with around 11 million euros assigned) that will run for the next 3 years and an **evaluation of ERNs** (5 years after their approval or last evaluation) with the objective to identify strengths and weaknesses and consequently the resources and efforts needed to cover the identified gaps.

## 6. Publication of the Updated EU NENs Policy Recommendations and the way forward.

The event **closed** with the **announcement** that the Neuroendocrine Neoplasms (NENs) Policy Recommendations will be soon published and a **call to action** to participants and NENs community for the continuous support to help disseminate the material and for the future engagement and events on tackling Neuroendocrine Neoplasms (NENs).

A follow up event is already being planned around the ESMO Asia Congress (the latter will be held in Singapore from 2 to 4 December 2022). By building on the example of the EU NENs Policy Recommendations as a case study, this will aim at presenting the updated NENs policy recommendations to the APAC audience to explore from an EU-Asia comparative perspective the synergies and the possible transferable experiences in the field of NENs.

# Neuroendocrine Neoplasms

## POLICY RECOMMENDATIONS

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