

POLICY RECOMMENDATIONS

on Neuroendocrine Tumours (NETs)

The European Union in the last thirty years has shown its commitment to fighting rare diseases and cancer through pioneering policies, but numerous challenges in the management of rare cancers such as neuroendocrine tumours (NETs) remain.

To tackle these challenges, healthcare professionals met with policy makers in the European Parliament on 10 November 2015. The stakeholders marked World Neuroendocrine Tumour Day and presented concrete policy recommendations on how NET care can be improved for EU citizens.

The stakeholder meeting in the European Parliament was chaired by Dr. Charles Tannock (ECR, UK), long term campaigner for better cancer care, and Ms. Françoise Grossetête (EPP, France), leading health policy MEP.

The codified recommendations outline the challenges of NETs, their impact on patient lives and the importance for support to research in this field, by addressing 3 main themes:

- 1. KNOWLEDGE IN DIAGNOSIS.** The very recognition of NETs and their timely diagnosis represents a significant challenge that can only be overcome through raising awareness amongst medical professionals. The identification of a rare condition from relatively common or ambiguous symptoms is a challenge which can only be met through clear guidance for GPs on the ground.
- 2. PATIENT JOURNEY.** Given the multidisciplinary nature of NETs, the care pathway is an essential focus of these Recommendations. The creation of centres and networks through which specialised experts can engage with all those who play a role in the care of NET patients, would represent a significant step towards improving care for NET patients in the long term.
- 3. RESEARCH AND INNOVATION.** Continuous research and innovation in this field is crucial to making positive steps towards improving cancer care. Member States must ensure that incentives are in place that encourage the development of new treatments for NETs and provide dedicated calls in research funding programs and EU funding schemes such as Horizon 2020.

The intention is to provide guidance to protect and improve human health through better management of conditions, contribute to EU and Member States' policy-making in the field and underline the need for mobilisation of all the Neuroendocrine community.

These policy recommendations represent a call to action from specialists in the field for Member States and the European Commission to ensure appropriate policies on NETs. Their direct implementation by decision makers can help ensure appropriate long term care for patients with NETs.

Recommendations Summary & Conclusions

KNOWLEDGE & DIAGNOSIS

Member States should support the NET community in its effort to educate healthcare professionals and foster knowledge-sharing on NETs regarding symptoms and diagnosis methods.

Member States that do not have a focused policy on NETs should consult specialists and utilise recommendations for best practices drafted by those specialists, based on their experience.

The NET community should work collaboratively on knowledge & diagnosis to identify recommendations for the European Union such as on hurdles to access to appropriate diagnosis and awareness raising on NETs.

PATIENT JOURNEY

European Reference Network covering NETs, as a more formal step for currently existing national networks would be beneficial and it is important that any future European Reference Network take into consideration the views of experts in this field and rely on already existing networks.

Considerable variation exists across Europe in the care pathway for NETs and it is important that best practices from different Member States are identified and disseminated, for example through EU initiatives such as CANCON.

A very effective way to improve treatment is to improve diagnosis of patients before tumours have spread to improve chances of surgery being possible.

Member States should improve access to specialist care effectively including surgeons, physicians and nurses. Standards of care developed by ENETs and national networks or centres of expertise should be utilised to fight inequalities in treatment of NETs in Europe.

Member States should support a multidisciplinary treatment approach for NET patients by including all relevant experts across disciplines to identify appropriate treatment.

Governments and healthcare providers must proactively consult NET patients and medical experts on NETs when elaborating policies affecting NET patients.

The NET community should work collaboratively on the topic of patient journey to identify recommendations for the European Union.

RESEARCH & INNOVATION

Member States should ensure appropriate incentives to support the development of additional treatment options.

The NET community should work collaboratively on research & innovation to identify recommendations for the European Union such as on an assessment of opportunities for support to research for NETs under Horizon 2020 and research funding programs.

Nothing about us without us! Organisations representing patients with NETs should be consulted on all policy and legislation that will affect NETs patients.