



Make Sense Campaign – Event Minutes

TRANSFORMING THE FACE OF HEAD AND NECK CANCER CARE IN EUROPE: IT IS TIME TO TAKE ACTION!

European Parliament Event

5 November 2019, 15:00

Objectives

1. Raise awareness of head and neck cancers in Europe
2. Transform the 'disease landscape' in this specific area of cancer

Patricia TOIA (MEP)

The EU has the best cancer care in the world. Ms. TOIA, as chair of the ITRE Cte fully supports the *Make Sense* campaign and pledged the continued support of both her group and her committee to various EU funding through *Horizon Europe* (2021-2027) for research in areas of “unmet clinical need” i.e. rare cancers and a recently allocated €10bn of cluster research into non-communicable diseases.

Dr Annalisa TRAMA (IRCCS)

When taken as a family, head and neck cancers (HNCs) are the sixth most prevalent form of cancer, but individually, each of the subtypes are rare. HNCs are associated with an overall poor prognosis with typical 40% rate of 5-year survival. Big differences across the EU stemming from quality of care. Dr TRAMA made reference to the Rare Cancer Agenda 2030 as part of the EU's *Joint Action on Cancer* (JARC).

Prof Lisa LICITRA (EHNCS)

Prof LICITRA stressed the issue of early diagnosis and quality of care, echoing the sentiments of Dr TRAMA. She pointed out that multi-disciplinary teams are required in the case of HNCs because no one physician is able to treat the disease alone. When this is done properly, the number of positive outcomes increases. Prof LICITRA demonstrated in her presentation some of the benefits of this kind of approach to both patients and clinicians. She gave the example of France, where drugs cannot be given to HNC patients without some kind of multidisciplinary assent being given.

Roberto PERSIO (HNC survivor – ECPC Member)

Mr PERSIO highlighted the need for survivorship care and support and highlighted the essential role of family and caregivers, particularly in terms of post-operative quality of life e.g. discrimination or psychological effects. He stressed that patients should be at the centre of a multi-disciplinary approach by being able to make informed decisions about their treatment and options. Mr PERSIO reminded the table that cross-border treatment is not always possible.

Antonella CARDONE (ECPC Director)

Ms CARDONE introduced the ECPC and its work and highlighted the ECPC's contribution and follow-up to JARC. Ms CARDONE highlighted the poor implementation of the cross-border directive and stressed the need to fill gaps in its implementation.



Prof Ana CASTRO (EHNS)

Prof CASTRO introduced the Make Sense campaign including its mission and goals and highlighted that multidisciplinary approaches to treating HNCs leads to the correct treatment options and better outcomes for patients. She highlighted the many achievements made by the campaign since 2013, particularly in terms of defining simple symptom check concepts and raising public awareness about HNCs in general. Prof CASTRO pointed out that for the work that still needs to be done, more knowledge about these rare cancers is needed.

Conclusion, Patricia TOIA (MEP)

Ms TOIA reiterated her commitment to setting up a parliamentary intergroup which would provide a forum of discussion among and between stakeholders and the European institutions.

Call to Action, Mark Dailey (Moderator)

Mr Dailey presented the call to action including the promotion of the messages about symptoms and risk factors of HNC on social media. He invited the audience to join the annual awareness week in September 2020. He urged them to become an advocate with stakeholders on a country-level.

Q&A Session

In the roundtable discussion, a representative of medical nutritionists referred to an ECPC survey on patient nutrition and asked whether nutritionists would feature as part of a multidisciplinary team treating HNCs. The panellists gave a unanimous 'yes', with Prof LICITRA pointing out that they were particularly important, since whole treatment regimens are constructed around a patient's weight which needed to be maintained where possible.