European Head and Neck Society Rue Héger-Bordet, 1 1000 Brussels Belgium

Ms Sandra Gallina Director General, Directorate-General for Health and Food Safety (SANTE) Rue Breydel 4, Breydelstraat 4 1040 Brussels Belgium

Mr John F. Ryan Director, Directorate-General for Health and Food Safety (SANTE) 11, Rue Eugène Ruppert L-2453 Luxembourg Luxembourg

September 21, 2021

## RE: European Head and Neck Society's *Make Sense* campaign outlines 5-point action plan during ninth annual head and neck cancer awareness week

Dear Ms Gallina, Mr Ryan,

You may recall we were in touch in February of this year to share our support for the comprehensive nature of Europe's Beating Cancer Plan and our recommendations for additional measures to ensure the best outcomes possible for people living with head and neck cancer.

After more than ten years of working for increased awareness of head and neck cancer and improved patient care as part of the *Make Sense* campaign, we were of course extremely pleased to see the inclusion of so many actions aligned with our own goals in the Plan, as well as an acknowledgement of the poor prognosis of this particular disease. We are writing to you today, seven months on, and during the ninth annual head and neck cancer awareness week in Europe, however, to request the renewed support of the European Commission for people across Europe living with head and neck cancer and the acknowledgement of our prior calls to action.

Head and neck cancer is the eighth most common cause of death due to cancer in Europe<sup>1</sup> but given many of the subtypes are classified as rare diseases, it continues to be a dangerously unknown public health issue. A recent survey conducted via the *Make Sense* campaign across 12 European countries highlighted the physical, social and professional impact of the disease on survivors, and flagged the worrying impact of the COVID-19 pandemic on those seeking support. Each year, the awareness week is an important time for us to educate the public on disease prevention, signs and symptoms, and encourage earlier presentation, diagnosis and referral, to ultimately improve outcomes for those diagnosed with head and neck cancers.

We strongly believe that real change can only come from a concerted effort from all parties, including those at a policy level. We therefore wish to take this opportunity to remind you of the ongoing desire from our community of healthcare professionals, caregivers and patients to see action and commitment from the Commission in helping us to tackle this devastating disease.

In September 2020, we launched our expert-authored White Paper, which was supported by Cristian Buşoi, MEP and Chair of the European Parliament Challenge Cancer Intergroup, outlining





the complex issues faced by those living with head and neck cancers in Europe. We have since received the support of more than 40 individuals and organisations throughout the European community, including healthcare professionals, patient advocates and members of the public, for the White Paper's recommended 5-point action plan, and we would like to remind you of what we, and our signatories, are calling for from the Commission:

#### 1. To actively engage in prevention strategies for head and neck cancer

This includes conducting awareness campaigns on head and neck cancer disease prevention, including tobacco and alcohol use, as part of the EU Health Programme 2021–2027; participating in, and supporting, the Make Sense campaign's annual awareness week for a collective approach on education activities; and supporting the HPV Action campaign in calling for the implementation of gender-neutral HPV vaccination in national cancer control policies.

#### 2. To support early diagnosis and referral to qualified healthcare professionals

This requires funding national screening programmes and endorsing the early detection and diagnosis of head and neck cancer as part of the EU Cancer Plan.

## 3. To promote multidisciplinary care as a standardised best practice approach for patients across Europe

This will rely on funding for the development of specialised high-volume treatment centres as well as education within the relevant specialities, and advocacy for multidisciplinary care to become a legal provision for patients at a national level, to ensure every patient has a multidisciplinary team in place throughout their journey.

#### 4. To advocate for the highest standards of post-treatment care

This includes supporting the development of head and neck cancer-specific survivorship guidelines and their integration into National Cancer Plans, as well as promoting and funding patient rehabilitation and survivorship programmes to drive engagement and increase compliance with ongoing treatment and care.

# 5. To dedicate EU and national research and innovation funds and support further research on head and neck cancer to improve prevention strategies, treatment options, rehabilitation, survivorship programmes, and ultimately outcomes, for all patients

This requires support at a policy level to foster an environment of data sharing and collaboration across expert centres for head and neck cancers and on an international level to assess quality of care and share learnings; encourage the generation of real-world data to better define head and neck cancers; and drive efforts to better understand the long-term health impact of intensive treatments used for advanced head and neck cancer.

With all of this in mind, we would like to invite you to meet with us to discuss the action plan, answer any questions you may have, and share further information on how we believe we can work together on our shared goals of improving outcomes for head and neck cancer patients and supporting caregivers and survivors. In the meantime, we would welcome your support to help us raise awareness during this most important week for the community.



### MAKESENSECAMPAIGN

#### Yours sincerely,



**Professor René Leemans** 

Make Sense Campaign Chair and Former EHNS President

Department of Otolaryngology Head and Neck Surgery, Amsterdam University Medical Centres, Amsterdam, The Netherlands



#### Professor Wojciech Golusiński

EHNS President and *Make Sense* Campaign Steering Committee Member

Professor and Chairman of the Department of Head and Neck Services of the Poznan University of Medical Sciences at the Greater Poland Cancer Centre, Poznan, Poland

**Professor Lisa Licitra** 

EHNS Board Member and *Make Sense* Campaign Steering Committee Member

Chief of the Head and Neck Cancer Medical Oncology Unit and Head & Neck Research Program, Istituto Nazionale Tumori, Milan, Italy

Associate Professor of Medical Oncology, University of Milan, Italy, and Scientific Director of the National Center for Oncological Hadron Therapy (CNAO)

#### About the Make Sense Campaign

The *Make Sense* campaign, initiated by the European Head and Neck Society (EHNS), aims to raise awareness of head and neck cancer and ultimately improve outcomes for patients with the disease. It will do this through:

- Education on disease prevention
- Driving understanding of the signs and symptoms of the disease
- Encouraging earlier presentation, diagnosis and referral

The *Make Sense* campaign is supported by Bristol-Myers Squibb, Merck and MSD. More information about the campaign is available at <u>https://makesensecampaign.eu/</u>, on <u>Twitter</u> and on <u>Facebook</u>.

#### About the EHNS

The European Head and Neck Society (EHNS) is an international non-profit association based in Belgium. The EHNS is composed of individuals, national and multinational societies, and associated study groups oriented towards head and neck cancer research, training and treatment throughout Europe. Individuals from the rest of the world are also welcome to apply for membership. The intent of the EHNS is to promote exchange of knowledge in all aspects of head and neck neoplastic diseases and to promote the highest standards of research, education and training, disease prevention and patient care. For more information on the society, please visit: <a href="http://www.ehns.org">http://www.ehns.org</a>.

#### **References:**

1. Ferlay J et al. Global Cancer Observatory: Cancer Today. Lyon, France: International Agency for Research on Cancer. 2020. Available at: <u>https://gco.iarc.fr/today/online-analysis-table?v=2020&mode=cancer&mode\_population=continents&population=900&populations=908&key=asr&sex=0&cancer=39&type=1&statistic=5&prevalence=0&population\_group=0&ages\_group%5B%5D=0&ages\_group%5B%5D=17&group\_cancer=1&include\_nmsc=1&include\_nmsc\_other=1. Accessed February 2021.</u>





#### Signatories to the Action Pledge

Anastasios Kanatas, British Association of Head and Neck Oncologists (BAHNO)	Jean-Pascal Machiels, Cliniques universitaires Saint-Luc
Boukje van Dijk, IKNL	Ana Joaquim, GECCP
Giovanni Succo, Candiolo Cancer Institute	Bernd Lethaus
Liz Yeates, Marie Keating Foundation	Jake Battersby, Make Sense Campaign
Joost van de Ven	P. Roelfzema, Patiëntenvereniging HOOFD-HALS
Ute Bauer	Stefan Hassfeld
Ester Orlandi	Francesca Caspani
Petra Scholz	Liesbeth Drenth, PVHH
Lennart Heinrich Pieper	Thomas Berger
Sylvie Averlant	Caroline Speksnijder, UMC Utrecht
Matilde Paolini	Marco Benazzo, University of Pavia
Lisa Licitra	Mark Goedkoop
Rob, PVHH	Ilaria Pellegrini, IRCCS Istituto Tumori di Milano
Michaela Ranta, LKH Feldkirch	Roberta Lombardo
Wojciech Golusinski, European Head and Neck Society	Antonello Manocchio, FONDAZIONE IRCCS ISTITUTO NAZIONALE DEI TUMORI
Wennie Duvalois	Else Panayi
Paola Goffi	Laura Locati, Istituto Nazionale dei Tumori
Viktor Kunz, Leipzig University Hospital, ENT- Department	Cristiana Bergamini, Fondazione IRCCS Istituto Nazionale dei Tumori di Milano
Theresa Wald	Laura Buehning
Paola Maggioni	Francesca Mazzetti
Ruediger Zimmerer	Imperia Nuzzolese
Puya Dehgani-Mobaraki, Associazione "Naso Sano"	



## MAKESENSECAMPAIGN