

MAKE
SENSE
CAMPAIGN2018
CO18
Results ReportCEHNS
EUDBAL MECK SOCIETY

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EXECUTIVE SUMMARY

Celebrating its sixth year, the *Make Sense* campaign has seen more people participate in 2018 than ever before. Over 200 people from across Europe have been planning and executing activities to drive awareness of head and neck cancer, encourage earlier diagnosis and referral, ultimately with the aim of improving patient outcomes.

The year kicked-off with the *Make Sense* Summit in Amsterdam in January. Over 40 campaign participants attended, including the Steering Committee, country EHNS representatives, patients, physicians, professional organisations and industry sponsors; it was the perfect opportunity to discuss the current state of head and neck cancer in Europe and identify the future direction of the Campaign and activities.

The Summit led to the development and launch of the digital campaign 'Unrecognisable', which was created to highlight that not only do head and neck cancers not get the attention they deserve from the public, but they can also leave patients feeling unrecognisable.

Thank you to everyone who worked tirelessly to execute activities for this year's Awareness Week for what has been another extremely impactful week! We look forward to working together again next year, as we keep fighting for a better future for head and neck cancer patients.



Thank you to everyone who made the sixth Awareness Week so successful! While we have come a long way and continue to accomplish more each year, we still have work to do as we continue to improve outcomes for patients with head and neck cancer.

 René Leemans, EHNS Past President and *Make Sense* campaign Steering Committee Chair



KEY HIGHLIGHTS



UNRECOGNISABLE







ONGOING PARTNERSHIPS

The Campaign continues to go from strength-to-strength due to the ongoing dedication from our partners across Europe, as well as new addition of Brazil.

Our dedicated partners include patients, healthcare professionals, professional organisations and industry sponsors.

For the past 6 years, the support and expertise received from both our existing and new partnerships have been invaluable to the Campaign, and have supported activities at both a local and European level.





HEALTHCARE PROFESSIONALS









MAKESENSECAMPAIAN It-21 September 2018





INDUSTRY SPONSORS

Head and neck cancer treatment is multifaceted and complex, and so is life after treatment. We are proud to be partners with a campaign that works so closely with patients, putting their interests at the core in order to improve outcomes.

> At Bristol-Myers Squibb, we are committed to changing expectations in hard-to-treat cancers and the way patients live with cancer. Patients are at the center of everything we do. Our vision is to increase quality, long-term survival for patients with cancer and make cure a possibility.

- Michael Axelson, MD, Head, Oncology Medical Affairs



We are proud to be a part of the *Make Sense* campaign for the second year running. The work and dedication of the Campaign to improve patients' lives is inspiring, and we continue to partner with the Campaign to promote not only a MDT approach to care but to raise awareness of the importance of using the best treatment options.

 Dr. Alastair Benbow Chief Development & Medical Officer, Norgine





Head and Neck cancer AWARENESS WEEK

#standuprorsurvivors

WE STAND UP FOR HEAD AND NECK CANCER SURVIVORS

Over the last decade, increasing numbers of people are surviving head and neck cancer.[1] It is important they receive the support they need to adjust to their new lives post-treatment.

EUROPEAN HIGHLIGHTS



HCP EDUCATION MULTIDISCIPLINARY TEAM (MDT) SESSION

A MDT session, 'Exploring the Power, Purpose, and Practice of an Integrated Approach to Care', was organised at ECHNO in Rome, Italy. An esteemed group of rising stars in the field of head and neck cancer guided participants through discussions on the importance of a MDT approach to care, as well as how we can improve outcomes for patients.



AWARENESS RAISING UNRECOGNISABLE DIGITAL CAMPAIGN

Patients often describe how their experiences with head and neck cancer can make them feel isolated and the many challenges it can create in day-to-day life. In light of this, the concept 'Unrecognisable' was developed to highlight the effects of the disease, continue to increase awareness of the disease among the public and unite the community by shedding light on topics not openly discussed.



EMOTIVE/SURVIVORSHIP SUPPORT COOKBOOK LAUNCH

The *Making Meals Make Sense* cookbook, developed in partnership with head and neck cancer patients and specialists, was launched on the second day of the Awareness Week. Alongside the nutritious recipes, it also included a section dedicated to sharing experiences of past head and neck cancer patients. This section was critical to help others identify with and feel part of a broader community.



PARTNERSHIP BUILDING EU PARLIAMENT EVENT

On 9 October, the *Make Sense* campaign in collaboration with the European Cancer Patient Coalition (ECPC) organised a roundtable to discuss how to promote a better quality of life for head and neck cancer survivors. Participants including MEPs, head and neck cancer specialists, patients and industry sponsors discussed the current unmet needs across Europe, and how new unified survivorship guidelines could better support patients.



Participating in the Campaign for the first time, the Brazilian Group of Head and Neck Cancer held a symposium in Rio de Janeiro (19 – 20 September), highlighting the results and best practices of the Campaign and how it can be implemented locally. Dr. Ana Castro, a representative of both the EHNS and the *Make Sense* campaign, participated and around 150 healthcare professionals were in attendance. The team also conducted a survey to understand the extent to which the Brazilian population are aware of head and neck cancer. The survey results will be used in campaign activities in years to come!



FRANCE

Once again, France had many hospitals take part, with a total of 116 hospitals distributing information materials and some providing early diagnosis clinics too. In several of the hospitals, stalls were organised with ENT surgeons, addictologists and oncologists providing information and answering questions about head and neck cancer to patients and families. Overall, 45,000 GPs were contacted to increase awareness of the signs and symptoms of head and neck cancer, but also to inform them about the Campaign itself. Finally, to engage with the public, a social media campaign took place resulting in over 19,000 impressions across LinkedIn and Twitter.

GERMANY

This was a special year for the *Make Sense* campaign in Germany. For the first time the team focused on giving a voice to survivors. A radio clip featuring statements from a head and neck cancer survivor and EHNS representative, Professor Andres Dietz, was aired on radio stations across Germany and reached more than 2 million listeners daily. The team also distributed more than 2,500 leaflets and posters to clinics to help raise awareness of the signs and symptoms, and importance of early diagnosis and treatment.

EINE FRÜHZEITIGE DIAGNOSE KANN LEBEN RETTEN ...



The Hellenic Cancer Federation (ELLOK) participated in the Campaign for the second year running, and launched an online campaign to raise awareness of the disease. The groups also developed a guide to encourage and support its members to initiate their own awareness raising activities. ELLOK's members organised presentations and workshops around Greece, and a 'Call to Action' to the Ministry of Health, in cooperation with medical head and neck cancer societies, was launched, to improve head and neck cancer care in Greece.



Public engagement was at the forefront of the teams' activities this year; Associazione Italiana di Oncologia Cervico-Cefalica took the reigns to organise interactive activities in ten cities across Italy. Information materials were distributed and passers-by were encouraged to take a photograph of their head through cardboard cut-outs of famous portraits and share on social media with the hashtag #tienilatestasulcollo (#keepyourheadonyourneck). Additionally, the Campaign kicked-off with a press conference on September 11 in Rome and throughout the Awareness Week, 21 centres offered either free early diagnosis screenings or shared educational information.



KAZAKHSTAN

Activities in Kazakhstan focused on early diagnosis screening, and out of the 517 patients screened this year, there was an increased referral rate compared to that achieved in 2017. The team attributes the increased referral rate to the Campaign and its efforts throughout the country. An educational conference, with more than 150 members from the MDT attending, was arranged to continue the discussion on head and neck cancer signs and symptoms, highlighting the importance of prevention and regular screening, as well as focus on treatment options.



The Campaign in the Netherlands centred on the launch of three innovative videos through traditional and social media. The videos showed how head and neck cancer could develop through the eyes of an observer, to promote the importance of knowing the signs and symptoms. The Dutch team also developed three patient case studies combining copy and visuals to raise awareness of the signs and symptoms and encourage the public to visit the Dutch patients' association website to find out more information.



Norway launched an early diagnosis campaign to shed light on the importance of HPV vaccination for boys aged 12, seeing as this year for the first time, 7th grade boys will be given the vaccine as part of an inoculation programme in schools. The Campaign wanted to highlight the disparity in treatment between girls and boys, as girls aged 12-26 get the vaccine, whereas only 7th grade boys will be receiving it. The Campaign consisted of several short films published on social media, reaching approximately 150,000 people! Building on the success of previous years, Norway also once again hosted a conference with approximately 200 participants, to discuss different topics within the head and neck cancer field.



POLAND

For the first time, a National screening programme for head and neck cancer was initiated and more than 1,200 people were referred for care. Campaign activities garnered extensive media interest, with 31 local newspapers, radio and TV stations publishing more than 85 clips and articles! Across Poland, 20 meetings took place with healthcare professionals, students, politicians, and the public, to share head and neck cancer knowledge and information regarding the screening programme, with 1,030 people participating.



PORTUGAL

In Portugal, campaign activities were led by the GECCP and the Associação dos Amigos dos Doentes com Cancro Oral. Activities saw the development of 12 stories from survivors, which were then promoted through a video, posters, and media interviews, to allow each survivor to share their experiences with the public. One of the highlights of the Awareness Week was the inaugural photography exhibition, "After Cancer, Life", at the Assembly of the Republic in Parliament, in which photographs of head and neck suvivors were showcased. However, activities did not stop after the Awareness Week inished. Currently in progress are several projects including educating children about the importance of oral cancer, a cookbook launch and a training programme for pharmacies.



On 13 September, a parliamentary event was organised by the Romanian Society of Oncology Pathology for Head and Neck, to focus on the importance of prevention and early detection, as well as a patient centred approach to disease management. It was hosted by Professor Florin Buicu, President of Health and Family Committee Deputy Chamber, and supported by Dr Diana Loreta Păun, State Adviser – Department of Public Health Romanian Presidency. For the remainder of 2018, the team will also be organising a cooking course to launch the 'Making Meals Make Sense' cookbook, as well as providing free early diagnosis screening clinics.





An outstanding 30 regions across Russia took part in the Awareness Week. In Moscow, a roundtable discussion, 'Early Diagnosis for head and neck cancer in Russia', took place in the public chamber of the Russian Federation, with leading Russian head and neck cancer specialists. Early diagnosis day clinics have always been a major part of activities in Russia and this was no different in 2018, with 122 clinics taking part, a total of 27,390 patients screened and 1,826 patients referred. Finally, on 24 September at the Russian State Parliament. Professor Igor Reshetov lead a session dedicated to the developments of oncological support and to demonstrate the latest surgical methods, he also performed a live surgery to remove a tumour from a patient.





The focus in Spain this year was providing information on head and neck cancer. Therefore, on September 18, a discussion was held at the University Hospital 12 de Octubre; several doctors from the multidisciplinary team of the hospital attended including, Dr. Mª Jesús Morales Vela (Physician/Primary Care Dentist), Dr. Silvia Sánchez (Rehabilitation Physician in the area of Phoniatrics), Dr. Ana Ruíz (Radiation Oncology), Dr. Lara Iglesias (Medical Oncologist), and Dr. Gavilanes (Otolaryngologist). The discussion lasted several hours during which doctors provided information about head and neck cancer. Additionally, on September 20 at the University Hospital of La Paz, an information point was organised to provide information and distribute materials to increase the awareness of the disease.

Turkey developed a film, 'Unrecognised', to draw attention to the challenges head and neck cancer survivors are faced with. The video has received an impressive response so far – 464,406 impressions and 239,936 views! Also during the Awareness Week, a press conference took place with leading key opinion leaders including representatives from the EHNS, Secretary General, Asia Pacific Thyroid Society and renowned medical professionals in Turkey, to raise awareness of head and neck cancers. The conference generated a high-level of interest among the media, with an estimated reach of 9 million people online and over 420,000 in print.





Activities focused on the launch of the first national level patient group in the UK, 'Head and Neck Cancers UK' (HANCUK). Led by former patients Chris Elkington and David Stanbury, the highlight of HANCUK's activities was a patient meeting at the Queen Elizabeth hospital in Birmingham. Patients from across the UK attended and guest speakers spoke on topics such as the role of the carer and psychological issues faced by head and neck cancer patients.



THANK YOU

A huge thank you to everyone who was involved in this year's campaign – your ongoing collaboration and hard work ensures that together, we keep raising awareness of head and neck cancer. It has been amazing to see your creativity and hard work come to life during the Awareness Week. The results speak for themselves, and we look forward to working with you all next year!

The *Make Sense* campaign is run by:



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