

MAKESENSECAMPAIGN



Results Report 2017

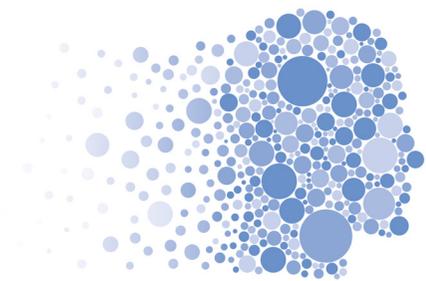
Contents

Executive Summary **3**

2017 Key Stats **4**

Partnership Spotlight **5**

Country Results **7**



MAKESENSECAMPAIGN

Understanding and awareness of head and neck cancer is evolving across Europe; however, variable incidence rates across the continent influence screening, treatment and care decisions. This is why education on preventative methods and the signs and symptoms of head and neck cancer is so vital, and is the main objective of the *Make Sense* campaign. The campaign's Annual Awareness Week aims to drive outreach to all regions and ensure everyone is adequately informed.

This year the *Make Sense* campaign reached another milestone – it celebrated its 5th Awareness Week during 18–22 September. Pan-European participation across 18 countries led to many successful activities, including screening programmes, educational lectures and widespread material distribution and media engagement, to drive awareness of the signs and symptoms of head and neck cancer, and promote earlier diagnosis to decrease prevalence.

The theme for this year was Supporting Survivorship, and activities focused on improving the lives of head and neck cancer survivors, by increasing understanding of the challenges and unmet needs faced. It was understood, after discussions with patients and survivors, that there is a need and demand for improved psychological and physical post-treatment support, but also that when faced with these difficulties there is great strength. Thus, we launched Survivors' Stories this year, in which 6 head and neck cancer survivors share their inspiring and raw journeys, from diagnosis to post-treatment.

To launch *Survivors' Stories*, an event was organised in the European Parliament, through our continued partnership and collaboration with the European Cancer Patient Coalition (ECPC). The event helped to promote the interests of head and neck cancer survivors in Europe, and lay the groundwork for unified guidelines to be developed. Event participants included Members of the European Parliament, head and neck cancer healthcare specialists and patients.

The strength of the campaign would not be as successful without our ongoing partnerships with committed stakeholders supporting European and national activities. In 2017, we were pleased to announce new partnerships with Norgine and Bristol-Myers Squibb (BMS), with whom we look forward to continuing our collaboration over the coming years, to maintain the momentum of the Campaign's unbreakable success.

We would like to thank everyone for their ongoing support and efforts in ensuring the *Make Sense* campaign was another success!



Every year we see an increase in Campaign participation and dedication to raising awareness of head and neck cancer. Our successes over the past five years can only have been achieved through the hard work and efforts carried out across Europe, which I sincerely thank you for. Our theme of this year, Supporting Survivorship, has opened eyes to the impacts of head and neck cancer, and we look forward to continuing to drive this awareness into next year.

Professor René Leemans

EHNS President and *Make Sense* campaign Steering Committee Chair



The 5th year has been our most successful yet, and it is great to look back on all the achievements of the campaign since its beginning in 2013. We hope to continue to expand our outreach to other countries in Europe, and potentially outside of Europe, to increase awareness of and education about head and neck cancer. Thank you to everyone for their hard work and dedication, and I look forward to seeing continued growth.

Professor Wojciech Golusinski

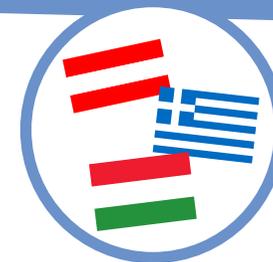
EHNS Secretary General and *Make Sense* campaign Steering Committee member

2017 Key Stats

4



>14,000
patients screened



**AUSTRIA, HUNGARY
AND GREECE JOINED**



>47,000
materials distributed



1,141
pieces of original
coverage generated

18
countries
participated
in 2017



**NUCLEAR MEDICINE AND
SENTINEL LYMPH NODE BIOPSY**
leaflets developed



33
patients and patient
advocacy groups
took part



Materials translated into
10 LANGUAGES



230
screening clinics



**ECHNO, IFOS
AND ORL-HNS**
congress attendance

Partnerships and collaboration are essential to the success of the campaign. Throughout our 18 European countries, we have dedicated teams who work tirelessly to execute activities and events to help raise awareness, build advocacy and effect change for head and neck cancer patients and survivors.



Boehringer-Ingelheim is proud to support the Make Sense campaign in raising awareness of head and neck cancer, ultimately aiming to improve patient outcomes.

Dr. Lef Zografos

Global Clinical Programme Lead, Boehringer Ingelheim Ltd



At Bristol-Myers Squibb, we are committed to advancing cancer treatments – transforming cancer into a chronic condition and even making a cure a possibility for many patients. We are excited and proud to be participating in the Make Sense campaign to drive awareness and education for head and neck cancers, encourage earlier diagnosis and referral, and improve care and outcomes for patients.

Dr. Salil Patel

Vice President, Headquarters Medical Oncology, Bristol-Myers Squibb

Those teams consist of EHNS members, physicians and other healthcare specialists, patients, survivors, patient groups and industry sponsors. The backbone of the campaign is the strength of our collaborations and partnership. This year, on top of our long-standing supportive partnerships with Boehringer Ingelheim and Merck, we were very happy to welcome two new industry sponsors and one new professional partner to the Campaign – Bristol-Myers Squibb, the European Association of Nuclear Medicine (EANM), and Norgine.



Norgine has a long history of actively working with patient groups and is delighted to support the Make Sense campaign. We believe that the campaign's awareness week was fundamental in improving the understanding of head and neck cancer, which is a complex disease and highlighting patients and survivors' experiences throughout their journey. We are looking forward to continuing our collaboration with the EHNS and the Make Sense campaign in the coming years.

Dr Alastair Benbow

Chief Development & Medical Officer, Norgine



We are extremely proud to have partnered with the Make Sense campaign since it's successful inception five years ago. The Campaign has played an incredible role in increasing awareness and improving outcomes for head and neck cancer patients. Our teams across Europe have contributed significantly to these awareness efforts over the years and we look forward to continuing our work together to improve care for head and neck cancer patients, from diagnosis through to post-treatment.

Maya Martinez

Global Head of Oncology, Merck

The Strength of Patient Support

6

The evolution of the Campaign over the last 5 years from across Europe has been truly inspiring. We hope to continue to engage new audiences and raise the profile of head and neck cancer.

Rob Burdorf
Chairman, Patiëntenvereniging HOOFD-HALS

My experiences have led me to help others who may be experiencing the same challenges. I want to help people find the strength within to overcome the challenges faced physically and psychologically and that is why I became involved with the Make Sense campaign.

Magali Mertens de Wilmars
Founder and Coach, Vie & Cancer

Our activities to support the Make Sense campaign were meaningful to continue engaging the Norwegian head and neck community. We are happy that our joint efforts to initiate free vaccination for boys have been successful; this is a great progress we are all excited to see.

Are Rydland
Director, Munn-og halskreftforeningen

Patient and patient group support for the *Make Sense* campaign is at the centre of why we do what we do.

The Campaign supports and provides an additional platform to share experiences which, in turn, help others and create understanding among the public. Patient participation spans across Europe, and the Campaign is always looking for new participants to join in the fight against cancer.

The *Make Sense* campaign relies on the ongoing contribution from patients, including the sharing of their stories, input in the development of new campaign materials, and simultaneously, reminding those battling with the struggles of the disease that there is a support network available. Overall, their patient perspective is key to understanding what is further required for post-treatment care.

As part of our ongoing collaboration and partnership with the Campaign, we organised an event, to promote a better quality of life for head and neck cancer patients and survivors. We helped spark discussion on diagnostic and preventative needs, and how a multidisciplinary approach will solidify effective post-treatment care. On behalf of patients, we will keep bringing the fight to Parliament to ensure patients are heard.

Lydia Makaroff
Director, European Cancer Patient Coalition

The Campaign is an important support network for patients and I will continue to work with the Campaign to ensure we too can provide support, and wipe journeys of uncertainty, and create a clear path to understanding.

Umberto Tassini
Head and Neck Cancer Caregiver and Rehabilitator

As Russia has one of the highest incidences of head and neck cancer, we hope our work and dedication will significantly lower this number by educating the public early on before the onset of symptoms. Preventative measures are and always will be the most effective means of action.

Olga Vostrikova
Project Coordinator, International Patient's Union, Russia

Austria

We were very excited to welcome the Austrian team in this year's Campaign activities.

Led by the Austrian Head and Neck Society, the team focused on educating other healthcare professionals about the early signs and symptoms of head and neck cancer, and the importance of a multidisciplinary team approach to care. They hit the ground running at a local congress and have made all their educational material readily available with easy to digest leaflets and videos.



2017 was the first year we participated in the *Make Sense* campaign and it's only the beginning. As a head and neck community in Austria, we have to work hard to continue educating and continuing to encourage earlier presentation and diagnosis. It was a great first year for us, and we are looking forward to many more.

Dr. Dietmar Thurnher

Germany

2017 was one of the biggest years for the German team.

Led by Professor Andreas Dietz, the team held 22 early diagnosis clinics across the country, produced seven engaging and informative patient education videos about head and neck cancer, told the story of one cancer survivor, Anke Steinbacher, and rounded off their efforts by engaging with the media. All materials were shared with the media to help educate their readers about head and neck cancer, and these materials will continue to be available on the *Make Sense* campaign website.



We make every effort to ensure those affected can return to their previous life after treatment with the least possible restrictions. For me, it is therefore more important than ever to carry out head and neck cancer education for the public. That's why the *Make Sense* campaign is so important.

Professor Andreas Dietz



Italy

The Italian Head and Neck Oncologic Society (AIOCC) sought to educate the public about the risk factors and prevalence of head and neck cancer by sharing a video across a variety of media channels.

The effective outreach of the video campaign led to over 700,000 views and publication in 24 newspapers, and Facebook recorded a boost of 800% new users. The team also launched an advertisement campaign in newspapers and online to increase the scope of education and awareness of the signs and symptoms and the importance of early diagnosis of head and neck cancer.



Survivorship, and supporting a patients' quality of life after treatment, is a truly important aspect to head and neck cancer. We continue to drive education and awareness of the disease, but we also need to speak up for those who have come out the other end and support them however they need. I am proud to be part of the *Make Sense* campaign for the fifth year in a row, and we will continue to provide the best for patients in the years to come.

Professor Lisa Licitra



Kazakhstan

The main focus for the Kazakhstan team this year was awareness raising, showcasing a video across clinics, a supermarket chain called 'Magnum', public transport, and local television channels in the cities of Shymkent and Karaganda.

The team did not stop there, and took to the streets to actively engage with the public through distribution and discussions in Almaty and Astana. Astana also had billboards and TV and radio advertisements displayed consecutively for a number of days to highlight the Awareness Week. Along with this public engagement, another key focus was early diagnosis clinics, with the implementation of 8 clinics in 6 cities, resulting in the screening of approximately 635 patients.



We are excited about the fantastic reception to the Awareness Week in Kazakhstan. We saw great engagement and a willingness to discuss the signs and symptoms and importance of early diagnosis. It is great to be part of the European head and neck community so we can all work towards better outcomes for patients.

Dr. Adilbayev Galym



The Netherlands

The Dutch team, led by the patient group **Patientenvereniging HOOFD-HALS** and **Dr Simone Eerenstein**, were focused on telling the stories of head and neck cancer survivors in The Netherlands.

First and foremost, the team conducted research to determine the level of awareness and knowledge of head and neck cancer. To help tell their story, the team used the research results to engage media, including TV, online and radio. Furthermore, the team gathered a choir of head and neck survivors, including those who have had their voices affected by their cancer, either because of damage or absence of vocal chords. The choir sang a well-known Dutch song called “Diep in mijn hart” to showcase their strength after facing the difficulties of the disease. To finish off the week, the team also developed emotive and striking patient videos, which were shown across Dutch media and used on various social media outlets.



We come together every year to support patients and survivors, and those who may be at risk. It is incredibly important to continue hearing stories about how head and neck cancer has affected the lives of people in Holland; it reiterates why we do what we do to raise cancer awareness.

Dr. Simone Eerenstein



Norway

The Norwegian team, led by **Munn-og halskreftforeningen**, the national patient organisation, kicked off the week with an event held in collaboration with the **Cancer Association**, the **Mouth and Neck Cancer Society** and the **Dentists Association Norwegian Medical Association**, inviting **200 healthcare practitioners to attend a launch meeting, which included a free cancer screening.**

Equally important was the provision to attendees of insights about the issues surrounding oral health during and after cancer treatment; 50% of the attendees were dentists, as they are vital to early diagnosis. Key results were also achieved throughout the week, including the approval of a centralised patient referral system across 5 university hospitals, and initiation of a nationwide HPV vaccination scheme for boys, funded by the National Budget for Health, starting from 2018.

Our activities to support *Make Sense* campaign Awareness Week were meaningful to continue engaging the Norwegian and Scandinavian head and neck community. We have had great success with a symptoms awareness and education programme, specifically about the early signs and symptoms of the disease, and we are excited to have HPV vaccination initiated for boys, this is great progress we are all very excited to see.

Dr. Oddveig Rikardsen



Poland

Every year the Polish team initiates a strong, patient-focused campaign that spans the nation, and this year was no exception.

One of the most exciting successes of the Polish team was the approval of a national head and neck cancer screening programme, which will become available from 2018. Funding for the programme is to be provided by the Polish government. Outside of the national screening programme, during the campaign, 16 centres resulted in 500 people being screened. Additionally, educating young people is always fundamental to the team's outreach efforts, and 12 schools organised head and neck cancer educational sessions. The successes of diagnosis and educational distribution was captured across TV and radio, with Professor Wojciech Golusinski, Secretary General of the EHNS and *Make Sense* campaign Steering Committee member, making a number of appearances. There were many activities organised by smaller organisations, and this year these included consultations with medical specialists, and a 'Run for Health' organised by the Medical University in Wroclaw.



We are thrilled to start the national screening programme for head and neck cancer in Poland. We wouldn't have been able to be this successful and bring such an important programme to life without being part of the *Make Sense* campaign.

Professor Wojciech Golusinski



Portugal

The group running this year's activities was The Head and Neck Cancer Study Group (HNCSG), which delivered a strong set of early diagnosis day sessions, including in Parliament, screening a total of 277 patients and carrying out 13 referrals.

HNCSG, as well as the patient group ASADOCORAL, gave lectures on the symptoms of head and neck cancer, to encourage early diagnosis and prevention. An impressive 2,000 leaflets were distributed and the team was heavily engaged on online channels, tweeting live photos and posting important statistics to increase awareness. Dr Ana Castro, a member of the EHNS and a *Make Sense* campaign Steering Committee member, was a key voice of the campaign across the country. She discussed the campaign across a variety of news channels and rounded off the week as a speaker at a free session at Quinta de BonjÓia.



Each year our *Make Sense* campaign activities just keep getting bigger, and we are really starting to see the traction in Portugal. The fifth year of the campaign was a great success with more people becoming actively involved and we hope to continue on this momentum for many years to come.

Dr. Ana Castro



France

Nationwide, France's participation has developed every year, with 100 centres taking part this year – an increase of 59% from 2014.

Hospitals from across the country held lectures and free screening, and screened an average for 100 people per centre. A core focus was to target general practitioners (GPs) with over 16,000 materials distributed to this important audience. As well as GP targeting, a social media campaign was initiated across all channels, and teasers were showcased on the website, to encourage engagement across the public.



General practitioners are important to ensure that people get accurately screened and referred thereby leading to early diagnosis. We are so proud to be part of the Campaign and it is in the growth of the activities that truly showcase the impact we are making across the country.

Dr. Beatrix Barry



Russia

The Russian team were hugely committed to educating about the signs and symptoms of head and neck cancer.

The week kicked off with a roundtable discussion in the Public Chamber of the Russian Federation. Participants included leading Russian specialists on head and neck cancer, and government officials. Other countywide activities included early diagnosis day clinics, a young person's education day, healthcare professional lectures, materials distribution and media events. The engagement and impact of the country's activities was enormous: 79 cities in 24 regions participated, over 11,000 educational information items were distributed; over 260 media events took place and 12,000 pieces of coverage were generated.



Russia actively supports the continental Awareness Week. The campaign involved more than 3,000 doctors and tens of thousands of patients, and identified up to 25% of chronic diseases. Preventative treatment is the main goal of our efforts.

Professor Igor Reshetov



Spain

The Spanish team expanded this year, with the inclusion of the patient group, APC, and to kick start their activities, the Spanish team focused on awareness raising by opening with two roundtables in a hospital in Madrid.

Roundtable participants involved professionals, patients, caregivers and the Spanish H&N Patients Association. Additionally, efforts were concentrated to highlight the importance of raising head and neck cancer awareness with a press conference – to help communicate our key messages to an important audience in Spain. The attendees included head and neck cancer organisations, industry sponsors and patients. These efforts paid off, as 62 original pieces of coverage were published – an amazing result.



We are so excited to be a part of the Campaign this year. It was amazing to see the positive engagement of attendees at our roundtables, who delved into important discussions surrounding this devastating disease. We will continue working towards earlier diagnosis and improving outcomes for patients and look forward to seeing what barriers we can breakdown in the years to come.

Dr. Jose Luis Cebrian Carretero



Turkey

The Turkish team focused their efforts on a big social media campaign, called ‘Let’s turn head and neck cancer UPSIDE DOWN’.

This year they followed the Turkish idiom of “Baş aşağı edin”, literally meaning upside-down, but using this term to refer to overthrowing a disease, disaster or difficulty. In their social media campaign, the team encouraged the Turkish public to post pictures and videos of themselves upside-down, which generated impressive results, including over 690,000 YouTube views and over 39,000 Instagram likes within only 2 weeks! To launch the activities, the team developed a film and included messages about supporting survivors to raise awareness of head and neck cancer and early diagnosis. The team’s campaign can be found on YouTube or Instagram with the hashtags: #başveboyunkanserlerini #başaşağıedelim and #SupportingSurvivorship



We are thrilled and excited to see the impact our social media campaign will have on the young people of Turkey. Early education and awareness of the signs and symptoms of head and neck cancer is imperative, and by using social media to encourage and engage our audience we are hoping to see a downturn in the incidence rates in Turkey. We have been dedicated to the Campaign for the last five years, and are excited to continue working closely and educating the people of Turkey.

Dr. Sefik Hosal

United Kingdom

The focus for the UK was to share the stories of survivors who have faced difficult journeys, but most importantly, of their strength in overcoming some of the devastating effects of the disease.

Survivors had the opportunity to speak with various media outlets across the country and encourage those who may be noticing some of the signs and symptoms to go speak with their doctor – early diagnosis is imperative to a successful survival rate. The media engagement in the UK reached over 4,330,000 people! Sat Parmar – a well-known maxillofacial surgeon based in Birmingham and a *Make Sense* campaign Steering Committee member – also participated in the media engagement to help people learn more about head and neck cancer and what they can do to prevent it. There were also of course activities conducted in Wales, Scotland and Yorkshire!



The reach of the campaign this year has been outstanding, and seeing its growth is truly inspiring. I enjoy being part of the Campaign, especially hearing survivors' incredible stories and continuing to work towards our collective goal of improving care for patients with head and neck cancer across Europe.

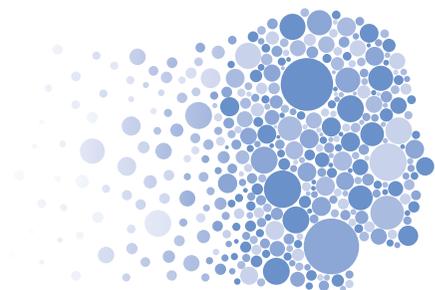
Dr. Sat Parmar



Czech Republic Non-EHNS Countries

The Czech team dedicated their activities to a non-profit organisation, called Liga proti Rakovině Praha – meaning League Against Cancer Prague.

Throughout the Awareness Week, healthcare professionals visited 8 cities to discuss head and neck cancer and with the general public and provide free screenings. At each booth, in each city, materials were distributed to help further educate. The team also saw success in their media efforts, with a press release being distributed and a total of 8 original pieces of coverage; the team is still conducting activities though and they are expecting to see even more results!



MAKESENSECAMPAIGN

THANK

you

We would like to sincerely thank everyone for their hard work and dedication in bringing together patients, physicians and organisations from across Europe. Through your creative and engaging activities, we believe that, together, we will be able to continuously reach new audiences and drive forward the campaign every year. We look forward to working with you all next year for another successful Awareness Week!

The *Make Sense* campaign is run by:



European Support for the *Make Sense* campaign is provided by:



www.makesensecampaign.eu



Secretariat@makesensecampaign.eu



[@MakeSenseCmpn](https://twitter.com/MakeSenseCmpn)



[Make Sense Campaign](https://www.facebook.com/MakeSenseCampaign)