

MAKESENSECAMPAIGN

Advocating for care that makesense

Make Sense Campaign Patient Advocacy Meeting

MEETING REPORT

Following a Patient Advocacy Meeting (PAG) roundtable meeting held in Bucharest, Romania, as part of the European Cancer Patient Coalition (ECPC) Annual General Meeting (AGM), the *Make Sense Campaign* secretariat coordinated a meeting of head and neck cancer PAGs in Madrid, Spain alongside the European Society of Medical Oncology (ESMO) 2014 meeting. The meeting offered the opportunity to all existing European head and neck cancer PAGs to collaborate for the benefit of patients across the region.

While there is representation for head and neck cancer patients at country level, a need was identified for a united network of PAGs to support people with head and neck cancer at European level in order to share current thinking and best practice. Head and neck cancer remains underdiagnosed, and those who are diagnosed require long-term support needs beyond their diagnosis and initial treatment.

MEETING OBJECTIVES

Prior to the meeting, the following objectives were set:

- To acknowledge common goals and common challenges
- To work together to find possible solutions and share new ideas
- To find ways where we can support each other in providing optimal patient care

MEETING OVERVIEW

The agenda for the meeting and included presentations from various European Head and Neck Society (EHNS) representatives, Umberto Tassini (Italian Association of Laryngectomees) and Jana Pelouchova (CML Advocates Network).

There was also an engaging break-out session focused on key themes and challenges facing head and neck cancer PAGS, as well as looking at ways to overcome such challenges.

After the break-out session the proposed network mission was presented and the group agreed in principle to the following:

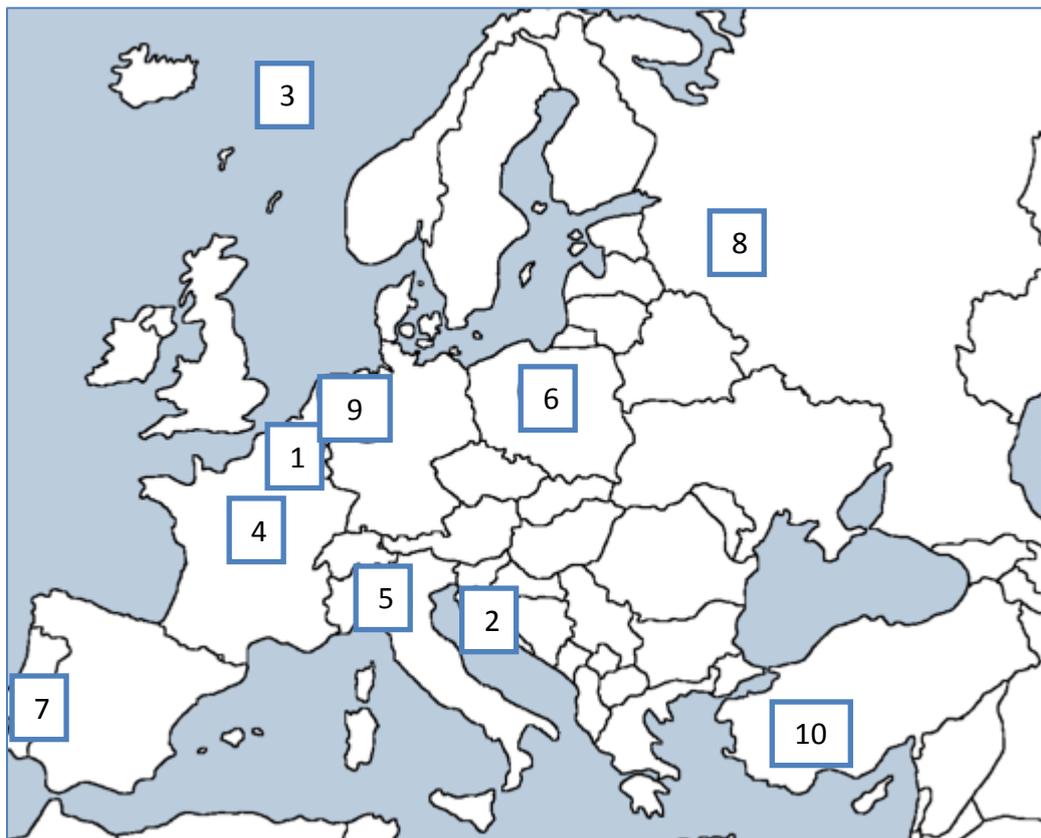
The *Make Sense Campaign* European PAG Network aims to provide the foundations to support and assist all patients with head and neck cancer across Europe to receive the best possible care. It does this through:

- Pioneering for optimal care for patients
- Working closely with the full patient care network
- Sharing ideas and knowledge to support best practices

The meeting was brought to a close with an overview of next steps for the network.

NETWORK FOUNDING MEMBERS

1. Belgium: AntwerpseVerenigingvoorGelaryngectomeerden
2. Croatia: Croatian Club of Laryngectomes
3. Europe: European Cancer Patient Coalition
4. France: Union des Associations Françaises des Laryngectomises et Mutilés de la Voix
5. Italy: FIALPO
6. Poland: Association of Persons with Head and Neck Cancers
7. Portugal: Associação dos Amigos dos Doentes com Cancro Oral
8. Russia: Help Patient.ru
9. The Netherlands: NSvG
10. Turkey: Dance with Cancer Association



BREAK OUT SESSION SUMMARY

Prior to the meeting a short survey was circulated to all prospective network founding members. As part of this survey respondents were asked to highlight challenges faced. During the meeting the results were presented and attendees were asked to contribute any further challenges not already identified.

The challenges that were identified prior to, and during the session are outlined below, alongside ways that the group suggested they could be overcome:

Challenge	Solution(s)
Financial support/funding for PAGs – operational perspectives	<ul style="list-style-type: none"> • Ensure that PAGs are well-equipped to develop persuasive and well-positioned project plans to secure funds from government or other industry sponsors • Training / guidance tools to be offered
Financial support/funding for PAGs – attendance at key events	<ul style="list-style-type: none"> • The European Parliament (EP) has grants available to fund patient advocates to attend congresses and meetings, and report back on news that will be useful for patients • Consider submitting applications for grants
Lack of disease awareness	<ul style="list-style-type: none"> • Host a gala dinner event near to EP with choir's from Croatia and Spain, alongside celebrities (potentially Celine Dion, due to her personal connection via her husband's experience of the disease) <ul style="list-style-type: none"> ○ Use the event to raise awareness and to raise money for patients ○ Invite media and MEPs • Develop some kind of online/viral awareness campaign based on the voice of a laryngectomised patients' 'sexy voice'
No centralised information portal for patients, HCPs and general public	<ul style="list-style-type: none"> • Develop an international multi-language PAG website, either standalone or in addition to the Make Sense Campaign site <ul style="list-style-type: none"> ○ Must have functionality to allow the patient advocates to communicate across different countries ○ Should include directory of European operational PAGs for patients to contact and list of centers where care can be accessed
HCPs and general public not informed about head and neck cancer patient, resulting in inferior	<ul style="list-style-type: none"> • Develop and launch 'emergency app' that Umberto suggested – which alerts passers-by to a potential emergency / a patient's need for

<p>emergency care, inability to communicate effectively</p>	<p>urgent medical care - available to patients who have lost verbal communication</p> <ul style="list-style-type: none"> ○ Develop stickers for cars, wristbands to indicate laryngectomy ● Launch the Merck Serono voice app in more languages, which helps patients to communicate following surgery, as they are learning to speak again
<p>Multiple groups not working together coherently, need for centralised communication channel</p>	<ul style="list-style-type: none"> ● PAG website, either standalone or in addition to the Make Sense Campaign site <ul style="list-style-type: none"> ○ Must have functionality to allow the patient advocates to communicate ● Identify at least one motivated and defined coordinator in each country <ul style="list-style-type: none"> ○ Run 'train the trainer' sessions to enable advocates to be able to train further people in their country ○ They can then co-ordinate other advocates locally and run small scale activities with supportive tools from network leadership ● Hold network AGM, first one to be used to develop 2015 plan, including: <ul style="list-style-type: none"> ○ Objectives and strategy ○ Review how groups can benefit from the Network ○ Discuss joint activities and opportunities ○ Review potential template materials
<p>Patients not sure where to seek support/where they can receive care</p>	<ul style="list-style-type: none"> ● PAG website, either standalone or in addition to the Make Sense Campaign site <ul style="list-style-type: none"> ○ Should include directory of European operational PAGs for patients to contact and list of centers where care can be accessed
<p>Support is vital throughout the patient journey, but is not always delivered</p>	<ul style="list-style-type: none"> ● Deliver 'expert patient programme' to up-skill advocates in market
<p>PAG leadership (may not be offering most beneficial support)</p>	<ul style="list-style-type: none"> ● Deliver expert patient programme to up-skill advocates in market ● Develop optimal PAG operating procedure in the form of European PAG toolkit

MEETING OUTCOMES

The format of the meeting allowed individual groups to acknowledge common goals and challenges and consequently work together to find possible solutions (as

outlined above). There was also enthusiasm seen amongst the group when sharing new ideas, for example holding a gala dinner with the laryngectomised choirs. The meeting also enabled the groups to identify ways in which they can support each other to provide optimal patient care.

NEXT STEPS

Formalise the Network by establishing a PAG network taskforce group as part of the Make Sense Campaign

- This group will be invited to participate in taskforce calls on a regular basis – to begin from January 2015

Topics of discussion for these calls should be focused on:

- Developing a platform for communications exchange amongst the group e.g., website
- Coordinating, organising and attending a 2015 planning meeting, which can be held annually thereafter
- Formally launching the network, e.g., gala dinner, viral awareness campaign, as part of the awareness week

