

# Cluster Headache Awareness Day 2018

## Declaration of Paris

We, the undersigned. Gathered on the 21<sup>st</sup> March 2018, the 3<sup>rd</sup> Cluster Headache awareness day. Members of the European Headache Alliance (EHA) Special interest group for cluster headache (CH SIG) representing national non-profit groups in 10 European or European affiliated countries have given our consideration to the management of cluster headache pain in Europe.

**The groups finding that cluster headache management is inadequate in most of the Europe because:**

- There is inadequate access to healthcare services for cluster headache (and other primary headache disorder) patients and failure to recognize that cluster headache is a serious chronic neurological health problem requiring access to management as other chronic diseases such as diabetes, or multiple sclerosis.
- The knowledge of healthcare professionals regarding the mechanisms, management and support of cluster headache is poor and requires to be improved.
- Cluster headache as a rare disease has a very low priority in the agenda of health authorities and of researchers.
- Cluster headache patients are often stigmatised, labelled drug seekers or completely misdiagnosed.
- Most countries have inadequate national policies about the management and workplace protection for those who suffer from cluster headache.
- Patient associations supporting those who suffer from cluster headache are often not adequately consulted about the implementation of healthcare policy plans for cluster headache in their national territories.
- The European Headache Federation states that more than 600,000 people in Europe live with cluster headache with less than 50% consulting a specialist and more than a third of patients missing work at a cost of 7bn euro per year.
- Cluster headache patients have poor access to accurate and reliable information about their pain and the available healthcare services for their disease.
- There are severe restrictions on the availability and affordability of effective symptomatic treatments and other therapeutic options critical to the management of cluster headache pain.
- There are unacceptable inequalities about the quality of healthcare assistance across Europe.

## **The Declaration of Montreal 2010 that Access to Pain Management is a Fundamental Human Right states:**

- The right of all people to have access to pain management without discrimination.
- The right of all people to acknowledgement of their pain and to be informed about how it can be managed and,
- The right of all people to have access to appropriate assessment and treatment of pain by adequately trained healthcare professionals.

**The group wishes that cluster headache patients are treated and managed in accordance with the declaration. In order to assure these rights for cluster headache patients we recognize the following priority for actions at European and national levels for shaping a painless future:**


1. Ensure that cluster headache, a rare but debilitating headache disorder, is formally recognised as a disabling condition and further ensure that national governments take into account that people who suffer this condition, often cannot work and require state support and assistance.
2. Ensure that spouses, partners and families of cluster headache patients are recognised as supporters and carers and are treated by their national governments as such and be offered all support and assistance available to that of a carer or supporter.
3. Ensure that cluster headache patients have equal and easy access to high quality healthcare and social care, without borders according to standards, guidelines, or best practice available for this condition, across the European Union and wider European Community.  
  
Abortive treatments such as high flow or ultra-high flow oxygen and sumatriptan injections should be available to all sufferers.  
Patients should have timely access to headache specialists should be guaranteed.
4. Ensure that research into cluster headache pathogenesis, diagnosis and innovative treatment options is supported, improved and coordinated across the European Union and wider European Community and that the patient organisation involvement is strengthened at every level of this Research.
5. Ensure that appropriate strategies to enhance the access to innovative treatments will be put in place in respective countries and encourage the establishment of specialised centres for headache, those centres should work together across borders to improve the condition of cluster headache patients.

6. Ensure that accurate and simple information is made available to patients enabling those who endure cluster headache to make factual choices according to their wishes will be available.
7. Ensure patient feedback is listened too and acted upon. Where organisations representing cluster headache patients exist that their advice and assistance is adopted to ensure healthcare is of sufficient and suitable for patients.
8. Ensure that initiatives raising awareness about cluster headache and other primary headache disorders will be promoted and encouraged.

**The EHA Cluster Headache Special Interest Group urges the national governments of the EU and wider European Community to agree to progress a pain free future for cluster headache patients.**

**EHF:**

**SFEMC:**

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Pneumatologue, Responsable la Résidence  
Rue de la Paix

**Physicians:**


Prof. DIMOS MITSIKOSTAS

 21/3/18.

Prof Delphine NAGIS .

 21/3/18 .

Dr Omberto DI LORENZO  21/03/2018

 Paul Rosh

Date : 21<sup>st</sup> of March 2018

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|  <p><b>EUROPEAN HEADACHE ALLIANCE</b></p>  |    |
|  <p><b>Organization for Understanding Cluster Headaches</b><br/>ONLUS<br/>Italia<br/>Organizzazione per la Comprensione delle Cause e Assistenza e Cura del Cluster Headache</p> |   |
|  <p><b>Bundesverband der Clusterkopfschmerz Selbsthilfegruppen – CSG e.V.</b></p>  |  |

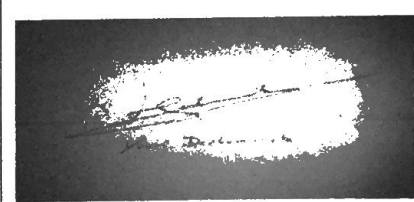
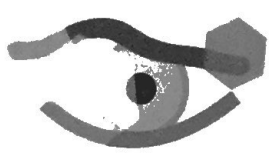


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[www.hoofdpijnvereniging.be](http://www.hoofdpijnvereniging.be)



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**AFCAVF**  
www.afcavf.org

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**U.C.H**  
**Belgium**

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**Supporting patients signatures:**

TESSIER Julien *[Signature]*  
Christine Joyeux *[Signature]*  
Franziska Giesecke *[Signature]*  
TERRIER Richard *[Signature]*

Mathieu COMARZEUKE *[Signature]*  
Camille ZINGRAFF *[Signature]*  
Nathalie SAURY *[Signature]*  
Beatrice SANCHEZ *[Signature]*  
Fiona SANCHEZ *[Signature]*

**Carers, family, relatives, friends ... signatures:**

North Tynish  
Anne Roman

