

## EHF News 22

### Surfing the web and...understanding Cluster Headaches

The Organization for Understanding Cluster Headaches (O.U.C.H.) is an international, not-for-profit advocacy group dedicated to providing support and information to people around the world who suffer from the poorly understood affliction commonly called Cluster Headaches, which has been described by one of its leading researchers as "probably the worst pain that humans experience", and to increasing public awareness of and research into Cluster Headaches.

"Suddenly a huge phantom bird sank three talons of its angry claws deeply into my head and face and tried to lift me. No warnings, no preliminary signs. Just wham! A massive, killing pain came over my right eye. I clutched my head, stumbled out to the broad lawns and over the hedges to the deserted tennis courts and then, there in the dark, I moaned, I panted. Ballooned my cheeks, blew out short bursts of air, licked my hot lips, wiped tears that poured out of my right eye, and clawed at my head trying to uproot the fiendish talons from their iron grip. One racking hour later the talons let go. The paroxysm eased as suddenly as it had convulsed. Euphoria set in. It's gone! Whopping headache, but it's gone!..."

Frank Capra, "The Name Above the Title"

(New York: Macmillan, 1971)

[www.clusterheadaches.org](http://www.clusterheadaches.org)

### Suffering from headache in Sweden

Svenska Migränförbundet, The Swedish Migraine Association was founded in Stockholm 1990. We have over 2.500 members and the organisation is represented by 16 regional branches out of a total of 21 in the country. There are several local groups and self-help also in operation. The board members are elected at a General meeting every two years. The board members in the regional Associations are elected every year. We publish and distribute a members magazine Migränbladet four times a year. Leaflets and newsletters are distributed to clinics, hospitals and the media in Sweden.

Svenska Migränförbundet also runs several information projects, eg. Childrens migraine and rehabilitation schemes for those suffering severe migraine headaches. A Migraine School has been succesfully driven since 1994 in southern Sweden. Full accomodation is provided over a 3 week period with expert staff, including doctors, nurses, physiotherapists and dietians. Our Association also offers a telephone help line and provides a homepage on migraine. Migraine meetings are held regulary around the country.

At the moment we prepare a press conference based on an inquiry sent to a part of our members. The event will take place late November and the purpose is to raise awarness of severe migraine headaches and focus on the DISABILITY in order to waken up the society from the top to the bottom. (We will be pleased to let you take part of the outcome of this conference later on).

As a new WHA member I learned a lot to learn from the Convention in New York last July and I will personally give a glimpsy from my impressions on the coming press conference. (What happened in New York since is a nightmare)

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