

Dear Friends,

People with cluster need your urgent help.

Several years ago the Centers for Medicare and Medicare Services (CMS) decided it would not pay for oxygen for the treatment of cluster headache. This is a serious hardship for many people with cluster headache. The American Headache Society and the Alliance for Headache Disorders Advocacy appealed to CMS to reverse this decision but they refused.

In February, we went to Congress, asking them to encourage CMS to reconsider this appeal. As a result of these efforts, Nebraska Senator Johanns and Delaware Senator Coons are circulating a letter for all Senators to sign urging CMS to re-evaluate this situation. To have the best chance of success, we need to have as many Senators as possible sign the letter.

Please contact your Senators and ask them to sign the Johanns/Coons letter encouraging CMS to cover oxygen for cluster headache. Below is a sample template letter that you should feel free to edit. If you can insert a personal statement about how cluster headache has affected you, your family member, or your patient, the email will be more powerful.

The deadline for the Senators to sign is Monday May 19 at 5:00PM!

Here is what you should do:

1. go online to your Senator's website. You can find the url here: http://www.senate.gov/general/contact_information/senators_cfm.cfm
2. click on email Senator
3. fill in your address and type in your request

Thank you!

William B. Young, MD
President, Alliance for Headache Disorders Advocacy

Here is a sample letter to cut and paste, with your own modifications into your email to your Senator.

Dear Senator _____,

Please sign the Johanns/Coons letter asking CMS to reconsider their decision to deny coverage of oxygen for cluster headache.

Cluster headache is one of the most painful conditions known to man. *[If you have a personal experience this might be a good place to insert it]*

Several years ago, to the surprise of the headache community, CMS denied coverage for cluster headache. The American Headache Society, and then the Alliance for Headache Disorders appealed, but their appeals were denied. This was particularly surprising because the Agency for Healthcare Research and Quality (AHRQ) lists oxygen as an appropriate acute therapy for cluster headache. The National Quality Measures Clearinghouse within AHRQ provides evidence-based health care quality measures and information for health care providers, health plans, and delivery systems. Also, the Veterans Administration provides coverage of oxygen for cluster headache. It is contradictory that a number of federal agencies have determined that oxygen is an evidenced-based treatment option and even disseminated this information in medical guidelines across the country, yet CMS has determined that this effective and low-cost therapy option should not be covered under Medicare.

Oxygen is the safest, and one of the most effective treatments for this condition, and it is also much less expensive than sumatriptan (Imitrex injections, the only FDA approved treatment for cluster headache).

By signing the Johanns/Coons letter, you will be helping hundreds of thousands of cluster headache patients who are affected by this misguided decision, or will be when they are on Medicare.

Sincerely,

Your Name