

The O.U.C.H. Newsletter

August 2007



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IMPORTANT NOTICE

This newsletter is written by Cluster Headache sufferers and supporters for other sufferers and supporters. The staff and contributors are not medical professionals. No information given here is meant to replace medical advice from your doctor or diagnose any condition. See your doctor before attempting any treatment changes. None of the treatments mentioned in this issue are endorsed by OUCH or any medical professional. OUCH does not officially endorse any advertiser and is not responsible for the content of any website advertised.



Organization for Understanding
Cluster Headaches

www.ouch-us.org

Announcements



Welcome to our New Members!

The past month saw 23 new members join our ranks.

Ohio - 1	Connecticut - 2	Poland - 1
Texas - 2	Oregon - 1	Italy - 1
New Jersey - 1	Louisiana - 1	England - 1
Arkansas - 1	Michigan - 1	Norway - 1
Pennsylvania - 1	Massachusetts - 1	Florida - 2
Indiana - 1	New York - 1	Illinois - 1
Alabama - 1	Nebraska - 1	

Welcome to you all, we hope you find the newsletter informative and helpful. If there is anything you can offer OUCH and you can spare any time we are always keen to have new people's talents to draw from.

If you would like to be put in touch with other sufferers in your state please let us know and we will do our best to get you together!

A warm welcome from the Newsletter Team!

From Your Newsletter Team

We regret that there isn't more information to be found in this issue. Between the OUCH Convention and related travel, family, medical and just life in general issues, the members of the newsletter staff have had their hands full this past month. The September edition will be a fully featured issue. Thanks for your understanding and patience.

Headache Diary Helps in Diagnosis and Treatment

Track your attacks and treatment effectiveness on this Headache Diary:

http://www.ouch-us.org/downloads/headache_diary.pdf



RichCon Remembered

The convention is over too soon as usual and everyone has gone their separate ways. As we think back about what we experienced, we feel a sense of melancholy and yearn to be back in the hotel. What a grand time was had catching up with old friends and meeting new ones. We remember the joyful and sometimes tearful expression in the new person's face as he or she realized they were no longer alone and remember how we felt when we met our first clusterhead or supporter.

Looking at the pictures from the convention brings a smile to our face and helps us remember we are not alone, so here are just a few pictures and comments from some of those who attended this year's OUCH convention in Richmond, Virginia.



Convention goes arriving at the hotel



Let's get y'all registered!

Meetings and technical sessions with various speakers during the day...



...good food and good company in the evening.



One of the whole gang



Getting ready to head for home & the dreaded "Long Goodbyes"



If you would like to host a convention close to you, please check out:

<http://www.ouch-us.org/gatherings.htm>

At the bottom of the page is a description of the selection criteria and what the host is expected to do.

Submit your proposal to the Convention Committee Chairperson at:

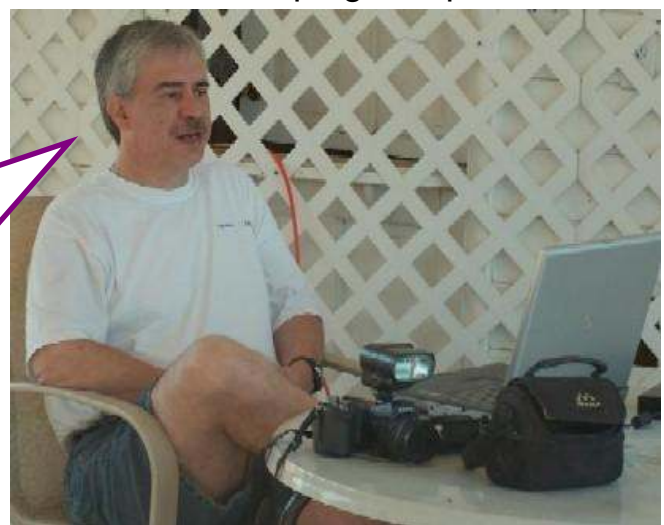
convention@ouch-us.org

Our correspondent in Richmond - "Thanks for keeping us updated, Bill!"

Well another OUCH gathering has come and gone. Funny how it takes so long for the time to arrive, then in a few short days it's over, and one is already thinking towards next year. Where ever the convention ends up next year, I'll be there.

...Suffice it to say that each one of you, old friend or new, holds a special place in my journey down the road of life. My life is richer due to each of you.

Bill (Racer1_NC)



Treatment News

Spotlight on Prescription Medications

Baclofen

Baclofen is a muscle relaxant and antispastic medication typically used in the treatment of pain, spasms, clonus and muscle rigidity in Multiple Sclerosis. Because it works at the central nervous system level, it may be useful in patients with spinal cord injuries. Baclofen has also been used, with limited success, in the treatment of Trigeminal Neuralgia.

Baclofen has been used with some success in treating cluster headaches (CH) in cases where the standard treatments have been ineffective. In studies, 66%¹ and 75%² of patients treated with 15mg to 30mg per day reported cessation of their attacks by the end of the first week.

The most common side effects of Baclofen are drowsiness, dizziness, weakness and fatigue. Other side effects may include confusion, headache (of course), insomnia, nausea, constipation and urinary frequency.

Baclofen is Pregnancy Category C, which means either 1. Animal studies have shown an adverse effect and there are no adequate and well-controlled studies in pregnant women. or 2. No animal studies have been conducted and there are no adequate and well-controlled studies in pregnant women. It should be used during pregnancy only if the potential benefit outweighs the potential risk to the fetus. Oral baclofen passes into the breast milk. Nursing mothers should take it only if the potential benefit outweighs the potential risk to the infant.

As with every medication, you should discuss what the drug is, what it is expected to do, how long should it take to become effective, side effects and drug interactions with your doctor and your pharmacist.

References:

1. Baclofen in cluster headache. Hering-Hanit R, Gadoth N., Headache. 2000 Jan;40(1):48-51.
2. The use of baclofen in cluster headache. Hering-Hanit R, Gadoth N., Curr Pain Headache Rep. 2001 Feb;5:79-82.

Need help with meds?

The Partnership for Prescription Assistance is there to help you find help in getting the medications you need with access to more than 475 public and private patient assistance programs.

Call 1-888-4PPA-NOW (1-888-477-2669) or check out:

<https://www.pparx.org/Intro.php>



Creative Corner

My Struggle

by Thomas Mikel

At night, it comes to me.
Possessing me, consuming me, ripping away my sanity, and everything that is good in the world fades to black.
I'm alone with my tormentor.
There is no help.
I must face it night after night. Alone.
No one understands the depths of my agony.
As I pace the floor in my own personal hell, I would do anything to make it stop.
I beg for mercy but to no avail, it doesn't listen.
The pain is more than I can stand. It's all that exists for me.
My world is crumbling away from me, and I don't even have the strength to hold the pieces together.
I wonder what I've done to deserve this. No one should have to endure this torture. It's just not fair.
It rips away my very sense of self, and leaves me a withered, wasted husk of humanity.
At times, I consider letting it win, giving up the fight, because I've lost the strength to carry on.
When will this be over? And when it's finally over, how will I ever be able to face it again?
The fear of its imminent return leaves me grasping for sanity.
Finally it's over. I'm exhausted, worthless, and unable to even pick myself up off the floor.
I rest and gather my strength for the coming day.
As I feel the dawning sunlight on my face, and bask in it's warmth, I think to myself, "It was worth it."
When the girl at the store, where I buy my coffee, gives me a bright smile, I think, "It was worth it."
A hug from a loved one, a laugh with a co-worker, a joke shared with a friend,
a distant relative's voice on the phone, answering a young child's question about life.
All of these things make the battle worth fighting.
You see it's not the pain that is important. It's the times when the pain is gone, that are important.
That's why I cherish every minute I have away from the beast,
because it's those times spent with friends and loved ones that give me the strength to continue my struggle.

**The O.U.C.H. website contains a section called
"Clusterhead Creativity" in the Members' Area.**

<http://www.ouch-us.org/members/membersarea.shtml>

**If you would like to share your original art, pictures,
stories or poems, please e-mail them to:**

webmaster@ouch-us.org