

The O.U.C.H. Newsletter

December 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



**Happiest Holiday
wishes from all of
us at O.U.C.H.
to all of you!**

**May the season be
blessed,
prosperous, and
pain free.**

O.U.C.H. News

Convention 2008 Site Announced!

After extending the deadline for bids several times, there were two serious bids for the site for the 2008 OUCH Convention: Portland, Oregon and Dallas, Texas. The author of the Portland bid, pulled the bid for the upcoming convention, leaving Dallas as the only submission, therefore, the site for the 2008 OUCH Convention will be Dallas, Texas. More information on hotel, registration fees, speakers and more will be reported as it is released.

If you would like to host a convention, **now** is the time to start thinking about 2009 and beyond.

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



OUCH "Volunteer Center" Opened

Volunteers are the backbone of any non-profit organization. The Organization for Understanding Cluster Headaches operates solely on volunteer labor. In order to help members decide where they might best fit in and to help OUCH recruit qualified, hard working people, we've made some changes to the Volunteer Application page in the Members' Area. Instead of a beg for help and an online form, visitors will now find an Organizational Chart, a list of Key Responsibilities and Position Descriptions for each committee and team, a copy of the OUCH Code of Conduct for volunteers, a Help Wanted section listing where help is needed and, of course, the Volunteer Application.

If you are interested in working with others to help OUCH fulfill its mission, please visit the OUCH Volunteer Center in the Members' Area.

http://www.ouch-us.org/members/surveys/volunteer_application.htm



O2 Users Support Team Gets New Leader

Steve Lichens is the new leader of the O2 Users Support Team. A big thanks to Steve for stepping up to do this! To contact Steve and the O2 Users Support Team, please e-mail

o2help@ouch-us.org

For information on using O2 as a CH abortive, check out the Support Team web pages at:

<http://www.ouch-us.org/medications/oxygen/o2info.shtml>

Announcements



Welcome to our New Members!

The past month saw 30 new members join our ranks.

Louisiana - 1	West Virginia - 1	Peru - 1
Kansas - 1	Texas - 1	Wales - 1
Maine - 1	New York - 2	Austria - 1
Georgia - 1	Massachusetts - 1	England - 2
Florida - 1	New Hampshire - 1	Romania - 1
California - 5	Michigan - 1	Australia - 1
Pennsylvania - 2	Indiana - 1	Canada - 1
Tennessee - 1		Finland - 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!

OUCH Family Services Team

Linda, Jackie, Cathi and Svenn want to remind you that they are there for you whether you need help finding information or just need someone to talk to. They can be contacted via e-mail at familyservices@ouch-us.org or online at:

<http://www.ouch-us.org/familysvs/familysvs1.shtml>

Community News

Getting Ready for DavCon '08

Excitement is building as clusterheads and their supporters gear up for the 5th Annual DavCon Meet & Greet, held in Davenport Iowa. This gathering, originally called the "Ch.com Midwest Meet and Greet," was initially started as a regional get together. After the first meeting someone coined the term "DavCon," and the name has stuck. DavCon has become a magnet for clusterheads from all over the US.

This year's gathering will be January 17th - January 20th, 2008 at the Best Western Steeplegate Inn. To make your reservations, call their Toll Free Reservation Line at: 1-800-373-6900. The room rates are \$89.99 for single and \$99.99 double. Best Western's worldwide give a 10% discount to people age 55 & over making the rate \$80.10 per night. Military members get the rate of \$60.10 per night. They also have corporate and AAA rates.

For those who will be flying in, the airport is MOLINE (MLI). This is actually in Illinois, but it's only a short distance to the State line.

For more updates and to see who is going, check out the DavCon '08 message board set up at Clusterheadaches.com:

<http://www.clusterheadaches.com/cgi-bin/yabb/YaBB.cgi?board=meetings;action=display;num=1184652007>

THE OUCH STORE IS OPEN!



[HTTP://WWW.OUCH-US.ORG/OUCHSTORE.HTM](http://www.ouch-us.org/ouchstore.htm)

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

Treatment News

Spotlight on Prescription Medications

Frovatriptan: The Travel Triptan!

For many people who suffer from Cluster Headaches, air travel is a major trigger. For myself, I'm guaranteed a hit within an hour of touchdown. I go out of my way to avoid connecting flights because it seems the more connections I make the more severe the hit I can look forward to. After responding to a post on this topic our own Helen (no surprise there huh) suggested I look into using FROVA™ when I travel. My doctor agreed and now FROVA™ is regular part of my travel arsenal.

Frovatriptan succinate is among the newest triptans available in the US. Like all triptans it is a selective 5-HT₁ (serotonin) receptor agonist and targets cells having multiple 5-HT₁ receptors. The difference between the various triptans is seen in how long they take to become effective and how long they remain effective. Unlike the fast acting, short lasting Sumatriptan (Imitrex™), frovatriptan takes two to three hours to become effective and remains effective for up to 25 hours. Up to three 2.5mg doses can be taken in 24 hours.

While you are much better off turning to Imitrex to abort an attack, the long lasting effect of this medication can be used in several ways.

1. For those with travel triggers, use it 2-3 hours before you know your plane is going to land. While air travel timetables can be hard to predict, it isn't typical that you land before you expect to.
2. To give a sufferer who needs some rest a good night's sleep, it can be taken two hours prior to bedtime. This preventative use is an adaptation of menstrual migraine treatment, which is typically given over a 6-day period. There is one study of 17 cluster headache patients that was done with promising results.
3. There is at least one migraine study out there that looked at mixing short acting triptans for fast relief with longer lasting triptans as a strategy to reduce headache recurrence and to cut down on the total number of doses of triptans used. The study involved oral sumatriptan and naratriptan. While I found ample evidence on message boards that some migraineurs regularly mix triptans, some with their doctors blessing, you won't find a doctor that will go on record against the Manufacturer's literature, which warns against it. Clearly this is an area that needs a lot more study. Who knows, as the various triptan manufacturers merge through acquisition, these restrictions may disappear, as it will open new applications for their existing medications. We can only hope.

As always, triptans are not to be taken lightly. They can have serious side effects. Persons with risk factors for coronary artery disease (uncontrolled hypertension, smokers, diabetes, obesity or a strong family history of coronary artery disease) should expect their physician to monitor their condition closely. This may include frequent blood pressure testing, stress tests and EKGs. These evaluations should be ongoing throughout treatment.

Although rare, cerebrovascular events and fatalities do occur with 5-HT₁ agonists. Cerebral hemorrhage, stroke and other events have been reported in patients treated with 5-HT₁ agonists. Some have resulted in fatalities. Though there were no occurrences in the more than 3000 patients with migraine who participated in the clinical trials of frovatriptan.

The most frequently experienced side effects are dizziness, abnormal sensations of the skin including numbness, tingling, prickling, burning, or creeping feelings, headache, dry mouth, fatigue, flushing, hot or cold sensation and chest pain. Less frequently observed side effects (<2%) were sleepiness and nausea. Overall, frovatriptan is generally well tolerated. The incidence of side effects did not increase when up to 3 doses were used in a 24-hour period. The majority of side effects observed was described as mild or moderate and didn't last very long. The occurrence of side effects did not seem to be affected by gender or age of patients participating in the study.

Frovatriptan is an FDA pregnancy category C drug which means - There have been no adequate, well-controlled studies in women, but studies using animals have shown a harmful effect on the fetus, or there haven't been any studies in either women or animals. Caution is advised, but the benefits of the medication may outweigh the potential risks.

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>

OUCH operates solely on donations, grants and sales from the OUCH Store. Donations to OUCH are tax deductible. Your generous gift to OUCH will benefit you in two ways - a break on your end of year tax liability and you'll be funding an organization that is working towards a better knowledge of the causes, treatments and one day a cure for cluster headaches.

Please help us help you by going to the OUCH Donations page and making a contribution today.

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

Christmas shopping with a Clusterhead.

By Dennis McCracken

It all came down to this one day, a list Christmas presents scattered across 15 stores in four cities in two states. Andrea and I had to persuade one older daughter and a future daughter in law to sit for the four little ones. We had 12 hours to get the job done. We had accounted for everything ... that is everything except an unscheduled, very persistent and very unwelcome shopping partner; The beast.

I knew I was in trouble when I got up that morning at 8:30am. I could feel him lingering there laughing at the list he was reading through my eye and planning how he would disrupt a day we could not afford to lose. I kicked myself having gone back to sleep after first waking up at 5:00am. A mistake I often make on cold Saturday mornings. I take a deep breath and think to myself, it's only a shadow and a shower will take care of that, I set the temp to hot and jump in. Then I set the temp to cold, still no relief. Out of the shower I'm now at a level 5 and climbing fast. After knocking back a Rock Star I hit the O2 and my poor wife walks into the bedroom, her smile falters as she hears the hiss of the tank and sees me sucking on the mouth tube. The excitement in her eyes is replaced with a pleading look that says "not today!". I nod and tell her it's going to be ok trying not to let my own doubts show. The only person I seem to be fooling is myself.

While packing water into the SUV for our trip I add my emergency kit; 1 e-tank with 15lpm valve, non-rebreather mask, three 16oz cans of Rock Star and a trex autoinjector kit with two 4mg doses. With my arsenal packed and ready I pop two sticks of gum in my mouth and start the engine.

We make it to Newburyport MA in a fruitless effort to find a small shop to pick up "something special" for my son Evan's girlfriend. We never find the shop. If only I'd checked Google for the address before we left. Oh yea, I wasn't thinking clearly was I. Round 1 goes to the beast. Andrea wants to keep looking but I convince her to look at the big picture. We'll get back to that one before the big day.

Off to Plaistow NH now. It's Walmart and Kohl's in that order. By the time we get out of the zoo that is Walmart my Christmas spirit is waning and my head is ramping up again. Have you wrestled through a self checkout with a long line of angry shoppers behind you yet? It's not for the faint of heart even without an advancing headache. I end up paying with the wrong card taking money out of checking instead of using a credit card as we'd agreed to use. Andrea innocently asks why I changed the plan and I snap defensively. I hate the way this pain in my head makes me interpret things said in the worst possible way. Ugly words are out of my mouth as if from another person. Fortunately for me, Andrea knows what is going on and waits for me to catch up with her. I apologize for my stupid response and she asks if I should hit the O2 again.

Once out of the Walmart parking lot I navigate through traffic slamming a Rock Star at the same time, drop Andrea off at the door to Kohls, park and break out the O2 for the 2nd time that morning – ok, it's about noon now. You get some pretty odd looks from other shoppers while sitting alone in your car sucking on O2. Fortunately no one stopped to offer any help.

Feeling better, my Christmas spirit returning I rejoin Andrea in the great Christmas present hunt. We finish at Kohl's and then get some lunch at Uno's; 1 large unsweetened Iced Tea, an onion ring appetizer to split and we each have a Spinach Chicken Gorgonzolla salad. You've got to eat light to travel fast. We always joke that the only time we get out to eat alone is when we are Christmas Shopping. It is fun to be a couple for a short while. Now I'm feeling really good and I have the beast on the run. (I think...)

After a quick stop at Working Gear we are onto the Rockingham Mall. Crowds are lighter than I expected. My biggest problem now is keeping fresh gum in my mouth and keeping my mind off the pain in my hands as I hold an ever increasing number of shopping bags. Aéropostale, Macy's, The Children's Place, Gap, Gap Kids, JC Penney... The list goes on.

Now we're heading back to Macy's for some perfume we forgot the first time we were there. On the way by one of the kiosks in the center of the mall Andrea notices a re-heatable beanbag that would be perfect for one of my daughters. Naturally, in order to buy what you want the vulture running the kiosk, a twenty something Russian girl, tries to up-sell us on "other items" she has. At one point, quick as lightning, she covers my face with one and tells me to breathe in. Turns out this one is full of pure peppermint oil. The beast leaps with joy as he's let out of his oxygenated, taurine reinforced cell and gleefully bites into the back of my eye. I gasp for air, let out a cough and the girl knows she's crossed a line. I don't remember paying. I don't remember what I said. I'm sure it wasn't nice. We head for the parking lot and the tools with which I'll rebuild his prison. The cold air outside helps too.

Another Rock Star and 20 minutes on the O2 and he's re-caged again. I'm exhausted but determined that we're gonna finish. It's now 8:00pm. We head back into Macy's, buy the perfume and four or five other things. We're now done with the mall and stop by KFC for a late supper. Not traveling so fast anymore we're in need of some serious sustenance.

Our last trip is to Methuen MA and The Loop to visit an Old Navy and Border's Books. Lots of clothes for the kids and some gift certificates for their teachers later we're finally done for the evening and there is no more sign of the beast. We head home exhausted but satisfied.

The three attacks I had that day weren't any different from any other day. I'm out of cycle now but I have bad days from time to time. It comes with the territory. It felt satisfying to get it all done in spite of my head. Never give up, never give in. I'm so happy to have Andrea in my corner. She is my anchor on reality when things start to spin out of control. I draw strength from the very sight of her. I wonder sometimes why she puts up with it all. Though I try not to ask that question too often Wink

We would like to thank all those who contribute their time, talents, information and research to the OUCH Newsletter.

If you would like to submit an article, story, art, poetry or whatever, contact us at newsletter@ouch-us.org.

Convention information can be found at:

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

How the Beast Stole Christmas

By Dr. Shoes

Every Head-Case in Clusterville Liked Christmas a lot...
But the Beast, Who lived north of My Eyebrow, Did NOT!
The Beast hated Christmas! The whole Christmas season!
Now, please don't ask why. No one quite knows the reason.
It could be his head wasn't screwed on just right.
Maybe his trigeminal nerve was too tight.
But I think that the most likely reason of all,
May have been that his pineal gland was too small.

Whatever the reason, His nerve or his gland,
On Christmas Eve he hated every ch'er in the land.
Staring down from our eyebrow's with a sour, beastly frown,
At the pain free delight that we wore like a crown.
He knew the ch'ers in Clustervilleville who,
looked forward to Christmas thanks to meds like O2.
"Their not even on PRED!" he snarled with a sneer,
"Tomorrow is Christmas! It's practically here!"

Then he growled, with Beast fingers nervously drumming,
"I MUST find a way to keep Kip 10's a'coming!"
For Tomorrow, he knew, regardless of sex,
Ch'ers would wake and they'd rush for their trex!
Then ch'ers, young and old, would rock for the Beast.
And they'd pace, cry and yell through the pain from the Beast!
They would swallow their triptans and reach for O2.
Which was something quite hated by old you-know-who!

And THEN They'd do something He liked least of all!
Every headbanger in Clusterville the tall and the small,
Would stand close together, with Christmas vibes sending.
They'd stand hand-in-hand. And their heads would start mending!
And the more the Beast thought of this Clusterhead ring,
The more the Beast thought, "I must stop this whole thing!"
"Why, for all of their lives they put up with it now!"
"I MUST stop Christmas being painfree! But HOW?"

Then he got an idea! An awful idea!
THE BEAST GOT A WONDERFUL, AWFUL IDEA!
"I know just what to do!" The Beast worked on his task.
And he made an O2 cylinder costume and mask.
And he chuckled, and clucked, "What a great Beastly wheeze!"
"When they can't have O2 they'll be down on their knees!!"

All their windows were dark. Quiet snow filled the air.
All ch'ers were all dreaming sweet dreams without care.
When he came to the first little house on his list.
"This is stop number one," the old Beasty Claus hissed,
And he climbed to the roof, empty tanks in his mitt.
Then he slid down the chimney. A rather tight fit.
But, if Santa could do it, then so could that %*it!!
Then he slithered and slunk, with a smile oh so rank,
Around the whole room, and he took every tank!
Imi, Olanzapine, Frova, O2
He stole all abortives from me and from you!

And he stuffed them in bags. Then the Beast, very nimbly,
Stuffed all the bags, one by one, up the chimney!
Then he slunk to the icebox. He took out the peas!
By hook or by crook he'd have them on their knees!
He cleaned out their red bull as quick as a flash.
Why, that Beast even took their last cigarettes and their ash!
Then he stuffed all the meds up the chimney with glee.
"And NOW!" grinned the Beast, "You will get on your knees!"

And the Beast grabbed the last bag and started to shove,
When he heard a small sound like the coo of a dove.
He turned around fast, and he saw a small ch'er!
Little Donna from Texas, the Beast's widow-maker!
The Beast had been caught by the OUCH president,
Who'd got out of bed to post a short vent.
She stared at the Beast and said, "\$%&*£er tell me why,"
"You think we will let you make our spirits DIE?"

But, you know, that old Beast was so smart and so slick,
He thought up a lie, and he thought it up quick!
"Why, Donna," the fake Beasty Claus lied,
"There's a bag of triptans that only abort on one side."
"So I'm taking them back to the doctor, my dear."
"I'll fix it up there. Then I'll bring it back here."
And his fib fooled the Pres – well she was half asleep
Then he patted her head, what a flippin' creep!

Donna went to bed with her water, water, water!
The Beast got the better of a true Texas Daughter!
Then the last thing he took was the Ice from the Freezer
He was a bigger Scrooge than even Ebenezer!
Then He did the same thing to the other ch'ers' homes
Leaving no meds to abort even for the Bone Domes!
It was quarter past dawn... All ch'ers, still a-bed,
All head-bangers, still a-snooze when he packed up his sled,
Packed it up with their triptan's, abortive's and pred!!
That rotten old meanie stole every last med!

"Pooh Pooh to Ch'ers!" he was beastily humming.
"They're finding out now that no Christmas is coming!"
"They're just waking up! I know just what they'll do!"
"They'll reach for syringes and Trex and O2!
Then the head-bangers in Clusterville will all cry "Boo Hoo!"
"That's a noise," grinned the Beast, "That I simply MUST hear!"
Your Christmas pain is my Christmas Cheer!!
And he did hear a sound rising over the snow.
It started in low. Then it started to grow.
But the sound wasn't sad! Why, this sound sounded merry!
It couldn't be so! But it WAS merry! VERY!

Meds aren't the only thing needed to make us pain free.
Support, love and friendship are what do it for me.
Through good times and bad we are here for each other.
The beast can not win when we're brother to brother.

He stared down at Clusterville! The Beast popped his eyes!
Then he shook! What he saw was a flippin' surprise!
Every Ch'er in Clusterville, the tall and the small,
Were singing! Without medication at all!

He HADN'T stopped Christmas from coming! IT CAME!
Somehow or other, it came just the same!
And cluster heads stood ice-cold in the snow,
And they hugged each other and felt their pain go!

"Pain free" came without ribbons! It came without tags!
"It came without stat dose kits, boxes or bags!"

The Beast puzzled for hours, till his puzzler was sore.
Then the Beast thought something he hadn't before!
"Pain Free," he thought, "doesn't come from a store."
"Being Pain Free...perhaps...means a little bit more!"

And what happened then? Cluster heads they still say,
That Clusterville sparkled with magic that day!
And when the Beast saw that amazing sight,
He exploded with rage and flew into the night.
The meds and O2 were left high on the Peak
So Donna took OUCH and those meds they did seek.
Ch'ers got busy making this Christmas the best,
The Beast tried to beat them but they thwarted his Quest!!

They all started cooking up food for a party
And banned Gator from Sprouts in case he got farty!!
Donna brought back the meds and O2 for the feast!
And smiled "Ain't that nice?!" as she carved the roast Beast!

Merry Flippin' Christmas from OUCH US!!