

# The O.U.C.H. Newsletter

## IN THIS ISSUE

OUCH News  
Cluster Stories  
Surgery for CH - Should I?  
Spotlight on Prescription Medication  
Creative Corner

**March 2008**



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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](http://www.ouch-us.org)

# O.U.C.H. News

## Convention 2008 Update

OUC is please to announce that the convention hotel is:

Embassy Suites Dallas - DFW International Airport South  
4650 W. Airport Freeway  
Irving, Texas 75062

The room rate is \$115 per night and includes:

Complimentary Full Cooked-to-Order Breakfast  
Complimentary Evening Manager's Reception (soft drinks, juices, full open bar, and dry snacks)  
Complimentary Parking  
Bus Parking Available  
Complimentary Shuttle to and from the airport or anywhere within 3 miles of the hotel.

You may start making reservations either by calling 1-972-313-8001 and using the Group Code **OUC** or you can make reservation online at:

<http://embassysuites.hilton.com/en/es/groups/personalized/DFWSHES-OUC-20080707/index.jhtml>

Currently, you can only reserve a King Non-Smoking via the web. For other room arrangements, please call 1-972-313-8001. We are working on getting this corrected and will post an update as soon as that happens. If anyone has ANY complications whatsoever with the booking process, please send an e-mail with your confirmation code detailing the problem to Donna Delacerda at [dd.ouch@gmail.com](mailto:dd.ouch@gmail.com).

### **Guest Room Features**

Two-room Suites  
Queen-Size Sofa Bed  
Refrigerator, Microwave, and Coffee Maker  
Two Televisions and Two Telephones  
Three Vanities/Sinks in each room

### **Hotel Facilities**

Indoor Heated Pool and Hot Tub  
State-of-the-Art Workout Facilities  
Capistrano's Restaurant  
Lynx Lounge  
Gift Shop/Business Center  
Access to the Trinity Railway Express to Dallas and Ft. Worth

### **Nearby Attractions**

Irving Mall and Movie Theatre	Ameriquet Field in Arlington	Six Flags Over Texas
Six Flags Hurricane Harbor	Texas Stadium	LoneStar Park in Grand Prairie
Advantage Sports Center	Dr. Pepper Stars Center	UTA
Golf Courses	Fine Dining, Casual Dining, and Fast Food Restaurants	

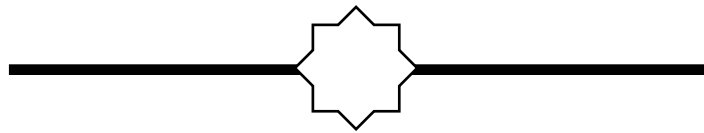
Further information on Convention Registration, Agenda, Speakers and more will be released as soon as possible. For more convention information, please check out:

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

# O.U.C.H. News

## **Welcome Back, Linda!**

OUCH is pleased to announce the return of Linda Howell to the Board of Directors. Linda will serve on the Board until the newly elected directors take office after the upcoming elections. Thank you Linda for your dedication and willingness to serve your fellow cluster headache sufferers.



### **Cluster Headache Medical Alert Form**

The worst time to have to explain cluster headaches to someone is in the middle of an attack. Complete this Medical Alert Form with your doctor and carry it with you. It will give E.R. staff your cluster headache related medical information and hopefully result in expedited and proper treatment.

**<http://www.ouch-us.org/downloads/ercard5807.pdf>**

### **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](mailto:familyservices@ouch-us.org) or online at:

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

# Cluster Stories

## Waking Nightmare

By Dennis McCracken

I awake uncomfortable from a dream. The dream is gone but the pain of it remains. My sleep drunk mind refuses to recognize the obvious. I roll to my right side and fool myself into thinking I can sleep again. Now I feel him, recognize him, fear him. He is already half way up Kip's ladder and drags me behind him. His hot oily grip firmly wrapped around my eye.

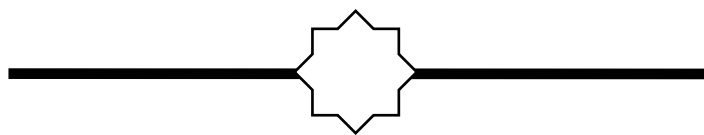
The fear and the pain provide a shot of adrenaline that gets my body moving. Coordination still isn't there. I fight with the sweat soaked blankets struggling to free myself. Trying not to wake anyone up, I make it to my bag of tricks in the hall. The noise I make brings a new voice to this barren world of heat and pain and fear. It's the voice of my Wife asking if she can help.

The beast screams in protest at this intrusion. He likes to be alone when he feeds on my agony. He wants me to lash out, to isolate myself from all that can help. I suppress the urge and say "no, go back to sleep honey". I have no idea how that sounded. Part of me cares deeply and some desperate, primal part of me doesn't. I'll apologize later. I'm always apologizing later.

I have the mask and stumble to the tank. I hear the merciful hiss of Oxygen running through rubber tubing. It's the sound of my fight to reclaim myself beginning. I love that sound more than is natural. Once mask is connected to tubing I begin to toll out my 50' leash. The pacing begins. Two passes later all that was in my way has been kicked aside.

10 minutes later I feel him leaving me, draining away. Was he really there? Am I still in bed dreaming? That has happened before. Wow my ankle hurts. How did that happen?

Within 20 minutes I'm tidying up, righting things that were knocked over. Whispering I love you's to a Wife once more disturbed. There is time to rest before the next round.



## 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](http://www.ouch-us.org/downloads/headache_diary.pdf)

# Surgery for Cluster Headache - Should I?

By: Mike Day

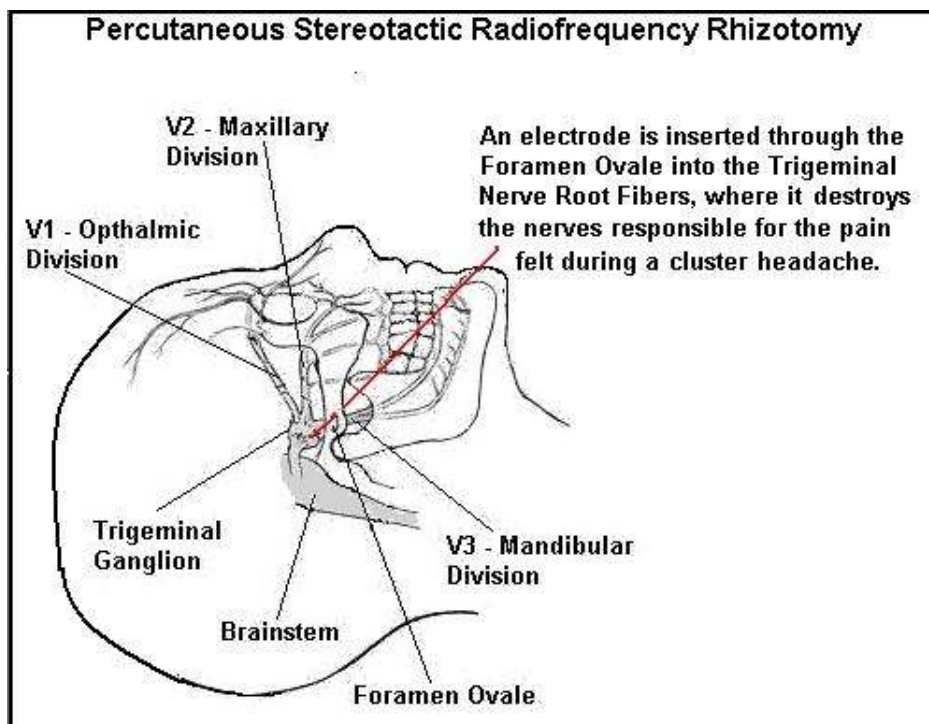
Surgery in Cluster Headache is typically reserved for only the most intractable of chronic CH patients who have exhausted all other medical options. Candidates must always have attacks on the same side of the head. Patients who experience attacks or cycles on alternate sides have a high probability of failure. Other criteria include pain localized to the ophthalmic branch of the trigeminal nerve, psychologically stable and have no addictive personality traits.

There are several surgical treatments for cluster headache, but are any of them a viable option? Only you and your doctor can make that decision. To help you decide, we are starting a series of articles on CH Surgeries. The information in these articles is not meant to replace information or advice from any medical professional. We encourage our readers to do their own research and to ask lots of questions with their doctors to ensure they make an educated choice based on facts.

We start our series with a look at:

## Percutaneous Stereotactic Radiofrequency Rhizotomy (PSR)

Until recently(?), this was probably the most commonly used surgical technique. In this procedure, a hollow needle with an electrode inside is inserted into the trigeminal nerve root fibers. To find exact placement, a low electrical current is passed through the electrode as the surgeon moves the needle/electrode to find the nerve root fibers responsible for the pain. Once located, short bursts of heat are applied to destroy selected portions of the nerve.<sup>1</sup>



Side effects can include loss of facial sensation, hyperacusis (over-sensitivity to certain frequency ranges of sound), tinnitus, moderate to severe facial dysesthesias (pain or unpleasant sensations that are produced in response to normal stimuli), corneal sensory loss, keratitis (inflammation of the cornea) and anesthesia dolorosa (severe spontaneous pain occurring in an anesthetic zone). Less common, but devastating side effects include infection, intracranial hemorrhage, stroke and motor weakness, which usually resolve in one to six months.

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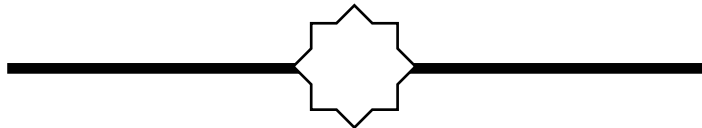
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Two series of patient studies demonstrated good to excellent improvement in approximately two thirds of patients. In one study, 27 patients were followed up for 6 to 63 months (median of 28 months). 15 had excellent results, very good in 2, good in 3, fair in 1 and poor in 6.<sup>2</sup> In another study, seven patients were observed for 2 to 20 years (median 5 years) – three had good (requiring medication) results and two had excellent (medication free) results.<sup>3</sup> Patients with pain centered around the eye had better results than those with major pain around the temple, ear and cheek.

*NOTE: While researching this treatment, I could find no recent research studies. The information here is based on articles ranging from 1988 to 1995 and the Mayfield Clinic website.*

References:

1. Percutaneous Stereotactic Rhizotomy: <http://www.mayfieldclinic.com/PDF/PE-PSR.pdf>
2. Percutaneous Radiofrequency Trigeminal Gangliorhizolysis in Intractable Cluster Headache; Ninan T. Mathew , M.D. and Wayne Hurt , M.D.; Headache. 1988 Jun;28(5):328-31. <http://www.blackwell-synergy.com/doi/abs/10.1111/j.1526-4610.1988.hed2805328.x>
3. Long-term Results of Radiofrequency Rhizotomy in the Treatment of Cluster Headache: Taha JM, Tew JM , Jr.; Headache, 1995 Apr;35(4):193-6; <http://www.blackwell-synergy.com/doi/abs/10.1111/j.1526-4610.1995.hed3504193.x?journalCode=hed>



### Spotlight on Prescription Medications

#### Zolmitriptan

By Dennis McCracken

In the last two issues we have covered Frovatriptan and Naratriptan. This month we take a look at Zolmitriptan.

Zolmitriptan is produced by Astra Zeneca and is sold in the US and the UK under the name Zomig. Zolmitriptan is available in 2.5mg and 5mg pill form and Rapimelt but we are most interested in the 5mg nasal spray. Repeat doses can be administered after 2 hours not to exceed 10mg in 24 hours.

Zolmitriptan nasal spray behaves very much like Sumatriptan in its fast onset of action, which can be as quick as 10 minutes. For patients who don't tolerate needles well or for patients for whom Sumatriptan has stopped working, Zolmitriptan can provide a good alternative abortive medication to Sumatriptan injections.

The usual dose is 1 spray into 1 nostril at the first sign of an attack. Try to alternate nostrils with each dose as serious irritation of the nasal cavity can occur over time. Each spray device contains 1 dose.

Blow your nose gently to clear the nasal passage. Remove the protective cap, and block 1 nostril by pressing firmly on the side of your nose. Place the tip of the spray device into the other nostril and breathe in gently as you press the plunger. Keep your head tilted slightly back, remove the tip from your nose, and breathe gently through your mouth for 5 to 10 seconds. You may feel liquid in your nose or the back of your throat. While this is normal, Zolmitriptan is designed to be absorbed by the nasal mucosa so you want to try to keep as much of the medication in your nasal passage as possible.

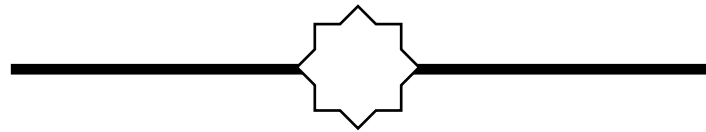
Zolmitriptan is a powerful vasoconstrictor. Triptans as a class can have serious side effects. Though during pre-marketing trials none of the 2,633 patients treated with Zolmitriptan found the side effects serious enough to discontinue treatment.

In a long-term study that followed 2068 patients over the course of one year, 8% (167) stopped treatment because of side effects. The side effects most frequently cited were paresthesias (tingling, pricking, or numbness of a person's skin), malaise/fatigue, nausea, dizziness, pain, chest or throat tightness or heaviness and drowsiness.

Persons with risk factors for coronary artery disease, which include uncontrolled hypertension, smoking, diabetes, obesity, or a strong family history of coronary artery disease, should be monitored closely by their physician. This monitoring should include frequent blood pressure testing and EKGs along with an annual stress test. These evaluations should be on going throughout treatment. For patients with risk factors for coronary artery disease, the Manufacturer recommends an EKG be given during an interval immediately following administration of Zolmitriptan to directly observe the effect of the drug on the cardiovascular system.

Although rare, cardiovascular events and fatalities do occur with 5-HT<sub>1</sub> agonists. Heart attacks and other events have been reported in patients shortly after treatment with 5-HT<sub>1</sub> agonists. Some have resulted in fatalities. Though there were no occurrences in the more than 2500 patients with migraine who participated in the pre-marketing trials of Zolmitriptan.

Zolmitriptan 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>**

## **THE OUCH STORE IS OPEN!**

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





# Creative Corner

## The Road Less Traveled

By Carolyn Morris



**Carolyn Morris is a very talented photographer and clusterhead supporter. Her work has been displayed in shows, won contests and will be published in the upcoming book, "Photography on the Net."**

**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](mailto:newsletter@ouch-us.org).**