

# The O.U.C.H. Newsletter

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

# O.U.C.H. News

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## **Election Cycle Changes**

At the Members' Meeting of the 2007 OUCH Annual Convention in Richmond, Virginia, the members in attendance were asked to consider and approve a measure to move the election cycle to coincide with the Annual Convention. Elections would occur in May and the first meeting of the new Board of Directors would take place at the convention where the outgoing officers and directors will pass the baton to the newly elected. This would allow for initiation and orientation of the new officers, directors and committee members at the convention. The new leadership would be presented to the membership at the annual members' meeting. The measure is also expected to help address a problem of low BoD output between October and the holiday season. The members in attendance approved the measure unanimously.

## **Changes in the Ranks**

Tony Amabile has been appointed as our new Convention Committee Chairman.

Brian Nemhauser, Certified Public Accountant and Financial Consultant, has been appointed as OUCH's Chief Financial Advisor.

Mike Day has returned to the OUCH Board of Directors. Mike has also been selected as the new OUCH Spokesperson.

## **Family Services Update**

Since January of this year Family Services has had 45 to 50 requests for help come through my contact e-mail with more than twice that amount, by checking the Guest book, ch.com, friends who ask me to help and of course all the newcomers. The requests for help range, from where to find a good Dr. or support group in their area to questions regarding their meds and treatment. Anytime I see a need from a supporter who is having a hard time coping, I give it to Jackie or Cathi to handle as they are two of the best when it comes to a soft shoulder to lean on, and I rely on Svenn to discuss more technical questions relating to CH, and I am on the phone to people all over the U.S. when it seems like they need a more personal contact than just e-mail.

I have a very good database that I am building so when someone asks a specific question I don't have to go searching for answers and continue to add to it when I see something of importance. If I don't have an answer for someone, I DO know where to find it or who to ask. Two of the contacts I had, resulted in convincing two families to come to the convention in July which really made my day and I hope theirs also.

My team and I abide by the HIPPA rules and each and every person who asks us anything is treated with respect and confidentiality.

Linda Howell, chair of Family Services

# OUCH Financial Report

The OUCH Board of Directors has released a financial statement for the first half of 2007. This information was reported to the members at the 2007 OUCH Convention. This information can also be found on the OUCH website at: <http://www.ouch-us.org/finreport.htm>

<b>OUCH - US</b> Cash Basis Financial Report <b>January - June 2007</b>	<b>Income / Expense Report</b>  <b>Year to Date</b> <u>Actual</u>
<b>Beginning Balance:</b>	<b>\$1,301</b>
<b>REVENUE</b>	Notes <b>1</b>
Contributions - General	286
Convention	1,518
Auction	213
Resale	209
Other Revenue	0
<b>TOTALS</b>	<u><u>2,226</u></u>
<b>EXPENSES</b>	<b>1</b>
Member Services	368
Education Services	72
Fund Raising	147
Admin & General	397
Miscellaneous	0
<b>TOTAL</b>	<u><u>984</u></u>
<b>Net Ordinary Income/-Loss</b>	<u><u>1,242</u></u>
<b>Ending Balance:</b>	<b>\$2,541</b>

Notes - Explained

- |          |   |
|----------|---|
| <b>1</b> | Unaudited figures   |
| <b>2</b> | An additional \$700+ is to be deposited in July from PayPals from Resale, Auction or Convention Registrations |

We would like to remind everyone that OUCH operates solely on donations, grants and sales from the OUCH Store. Donations to OUCH are fully 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>

# Announcements

## Welcome to our New Members!



The past month saw 36 new members join our ranks.

Ohio - 1	Colorado - 1	Florida - 1
Arizona - 3	Indiana - 1	Massachusetts - 1
Idaho - 1	Louisiana - 2	Canada - 5
New York - 2	Missouri - 1	England - 2
California - 1	Washington - 1	The Netherlands - 2
North Carolina - 1	Texas - 2	Turkey - 1
New Jersey - 1	Illinois - 1	Scotland - 1
Minnesota - 2	Georgia - 2	

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!

### Help Wanted!

The OUCH Newsletter Team is looking for two new team members who can research and report on cluster headache related information and other items of interest to our readers.

Candidates must be able to devote at least a couple hours a week to the team, interact via message board, e-mail and chat and communicate well in writing. A good sense of humor and the ability to laugh at yourself would be a great asset as well.

If you are interested, please go to the following address and complete a volunteer application.

[http://www.ouch-us.org/members/surveys/volunteer\\_application.htm](http://www.ouch-us.org/members/surveys/volunteer_application.htm)

You must be an OUCH member registered in the Members Area to access this page

## Treatment News

### Spotlight on Prescription Medications

#### Methysergide Maleate

Methysergide Maleate is a semi-synthetic compound structurally related to ergotamine. It is a serotonin antagonist and powerful vasoconstrictor used in the treatment of vascular headaches, including cluster headache. It is specifically designed for preventative treatment and should not be used as an abortive medication. As with most drugs, the method of action is not completely understood, but basically, it blocks serotonin, which is believed to be directly involved in the activation of the pain mechanisms in cluster headache.

The typical dosage for cluster headaches is 2mg to 6mg daily, taken at regular intervals with meals. If there is no benefit noted within three weeks, there will likely be none and the drug should be discontinued. Patients taking methysergide must take a "drug holiday" from this drug for about 4 consecutive weeks every six months to avoid developing Retroperitoneal Fibrosis, Pleurpulmonary Fibrosis and Fibrotic Thickening of Cardiac Valves.

Side effects can include chest pain or tightness, cold hands or feet, confusion of hallucinations; leg or arm pain or cramps; swelling of hands, ankles or feet; tingling, pain or numbness in feet or hands; nausea; vomiting; diarrhea; heartburn and weakness.

Because of its powerful vasoconstrictive properties, patients must not take medication containing triptan or ergotamine compounds such as Imitrex, Zomig, Axert, Amerge, Frova, Relpax, Maxalt, Cafergot and DHE within 24 hours of methysergide. Serious cardiac complications may result in the combining of any of these medications within 24 hours of each other.

Methysergide is Pregnancy Category X, which means studies in animals or human beings have demonstrated fetal abnormalities, or there is evidence of fetal risk based on human experience or both, and the risk of the use of the drug in pregnant women clearly outweighs any possible benefit. The drug is contraindicated in women who are or may become pregnant due to its oxytocic actions.

Nursing mothers should not take methysergide, as ergot alkaloids, in general, appear in mother's milk. Since methysergide is structurally related to ergotamine, it may appear in breast milk. Ergot alkaloids have been reported to cause nausea, vomiting, diarrhea and weakness in the nursing infant and suppression of prolactin secretion and lactation in the mother. Because of the potential for serious adverse reactions in nursing infants from methysergide, a decision should be made whether to discontinue nursing or to discontinue the drug, taking into account the importance of the drug to the mother.

This medication is no longer available in the US under its retail name of Sansert, but is still available in generic form through compounding pharmacies.

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.



# Cluster Headache, Dreaming & Neurogenesis

(last in a series)

by Peter May

## Chapter 16: Summary and Conclusions

This 'paper' was cobbled together from various sources, mainly from the internet, over the last couple of years or so. Accordingly, much of the information cannot be validated as being strictly accurate and hence many errors may be apparent. In previous chapters I attempted to pull all the relevant information together as quickly as possible and therefore many apologies for any specific plagiarism and for the lack of appropriate source data; but naturally I am greatly thankful to those individuals and organisations that had already summarised much of the information I have used.

Like most of my theories, much of the previous information is based on conjecture and is purely hypothetical. As you will have seen I am not a scientist, particularly in terms of neurology and chemistry, but here is the overall summary:

- Cluster headache (CH) is a devastating and disabling disease for many sufferers with as yet no known cause. A specific abnormality within the hypothalamus is likely to be important in its pathophysiology, but a dysfunctional pineal gland and associated systems may also warrant further investigation.
- All the previous evidence suggests that no one truly understands why we sleep, and more particularly why we dream; but most specialists do not deny the importance of both sleep and dreaming.
- There are a number of endogenous neurotransmitters and neurohormones that play an important role in sleep, and possibly dreaming. Many of these also play a role in the pathophysiology of CH.
- Sleep and wakefulness is determined largely by the hypothalamus which is linked directly to the pineal gland.
- It has recently been ascertained that neurogenesis can and does occur in various parts of the adult brain. How this mechanism works is not precisely understood.
- REM sleep, or more particularly any form of dream sleep, may promote neurogenesis in the adult brain. This may be associated with various 'dream transmitters' produced endogenously through the pineal gland.
- Dream transmitters have been hypothesised to be associated with mitosis, a key element to neurogenesis. If levels of dream transmitters are low then perhaps the brain may need to re-adjust accordingly.
- Neurogenesis has been associated with biochemical interaction with entheogenic drugs. Some of these drugs are possibly the most effective treatment of CH, and although their mechanism of action is poorly understood, they may well be working by mimicking the previously discussed dream transmitters.

So in summary, the current theory is based on the hypothesis that the pineal glands' of CH sufferers are malfunctioning in some way, which in turn leads to an imbalance of certain neurotransmitters, neurohormones and possibly catalyst enzymes. The various types of psychedelic drugs or entheogens used for the treatment of CH may actually work by mimicking some of these chemicals, particularly those that may be produced by the pineal gland.

The reason why this medication works better than most conventional treatments is that they do not just abort individual attacks, and prevent further bouts from occurring, but also continue to work long after the effects have left the body. I think they do this by actually helping repair specific areas of the brain whilst sufferers sleep, but perhaps more importantly through the action of 'waking dreams' whilst the medication is taking effect.

There may not be much that CH sufferers can do currently about an abnormal hypothalamus, or indeed a malfunctioning pineal gland; but perhaps one day, bearing in mind recent developments in stem cell research and possible nanotechnology in neurosurgery, this may well change. In the meantime, entheogenic treatment therapy appears to be the best way forward for many cluster headache sufferers. Sweet dreams.

Many thanks to:

*Bob Bowling, Jonathan Byron, Helen Kemp, Ben Khan, Bob Wold, James Joseph, Pinky*

**Peter May is a former chronic sufferer who has been researching CH since 1990 with a view to helping other sufferers gain a greater understanding of their condition.**



We are always looking for fresh research into the causes and treatment of cluster headache. If you would like to submit an article you think will help other sufferers and/or supporters, please send it to [newsletter@ouch-us.org](mailto:newsletter@ouch-us.org).

**Cluster headache supporters have CH, too - Caring Hearts**

**Have you hugged your supporter today?**

**NO WAY.. the adventures of an agoraphobic clusterhead.**  
**by Anthony Amabile**

I paced feverishly through the night gripping my head and letting out a low guttural moan. Wanting desperately to not disturb Ben or the animals in the next room, I clenched my lips shut tightly to muffle the noise and drew a little blood as I bit down hard. This was a repeat of so many nights before, the anxiety that rushed through me made my heart pound and my chest ache... My thoughts were racing in a thousand different directions and each mocked me with its speed as I felt compelled to inspect each one... they were too quick... they mocked and raced.. never slowing and never showing mercy.

The night carried me along as a passenger train through tunnel after tunnel of dread over the blur of an unknown yet familiar landscape. My chest tightened. My pulse raced I can only describe it as the feeling one gets when going down a large hill on a roller-coaster... a 3,000 mile very steep hill. Tomorrow I was leaving for Norway.

The sun rose to find me exhausted and twitching on an uncomfortable tangle of sheets and bed clothes I was irritated and I could just make out the almost inaudible sound of a crying baby... as the veils of sleep lifted and the sound grew louder... I remember thinking to myself.. "Baby? I don't have a baby." Then my face was stung with a cold wet dauber. My lids sprang open and Oscar came slowly into focus. Oscar had to pee. It was time for me to get up and as I ratcheted off the bed and made my way down the hall I nearly tripped over my luggage... I had to struggle to try to remember packing... then the memory hit me and knocked the wind out of me again. I'm going to Norway! OH MY GOD>>> WHAT WAS I THINKING?

I opened the door to let Oscar out to pee and let in a strong rush of "What ifs"! What if the house burns down while I'm gone? What if something happens to Ben. What if Oscar gets sick? What if the aquariums fall over and crush my cats? What if the sewers back up? What if the television explodes and cuts Ben's jugular vein and he dies and the dog eats him and then the crushed cats... and then what if the dog bleeds to death from swallowing the broken glass that he consumed while eating Ben and the cats? What if Oscar knocks the phone off the hook after he eats Ben making everyone who calls think that Ben's okay but just on the phone? What if while I'm going to the car with my luggage a satellite falls to earth and rips it? What if the grass dies while I'm gone and the neighbors get upset? What if a truck tire explodes while we're driving past it on the way to the airport? What if I forget to turn off the coffee pot and have to turn around and by so doing I then get hit by an exploding truck tire? What if the toll booth tips over instead of the toll gate after I pay the toll and crushes me? What if the car explodes after the toll booth tips over and crushes me... destroying all of my teeth and identification? What if there's a bizarre earthquake at the airport and my plane cracks, just a little... and what if the crack is near my seat and I get sucked through it and into the jet engine? What if I get a cluster attack while going through security which prompts them to do a deep body cavity search? What if the large mole covered security officer has poison ivy on her hands and is wearing a faulty latex glove? So many what ifs.... all going by so fast and as they rush by, my heart pounds harder and my chest tightens and I begin to sweat... and the room closes in on me.... I need to make some coffee.

My flight was leaving in five hours and I'm not sure what I packed... I need to empty my luggage and repack it... again and again and again.

..... to be continued



## Creative Corner

### *Battle Dance*

*The pain resounding ever still  
Watch for the time when all is still.  
Can you maintain your constant vigil  
Try to stay alive.*

*The time you battle short to some  
Intense your fight not to be overcome.  
Rock so to keep an upper hand  
To what end do you strive.*

*Waltz around the tiny floor  
Pray no one comes through the door.  
Dance you must from your very core  
To the end you will arrive.*

*Breathe the clean untarnished air  
Your battle plan does not seem fair.  
The weapons you keep close to bare  
Humming like a hive.*

*Fall back into ranks of many friends  
The battle will reach an end.  
Exhausted you will soon depend  
Help will soon arrive.*

**Mike**

aka Ghost on [www.clusterheadches.com](http://www.clusterheadches.com)

**Share your talent with us.**

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photography, poetry and  
stories to:**

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