

The O.U.C.H. Newsletter

November 2007

IN THIS ISSUE

OUCH News

Supporter Appreciation Day
Announcements

Treatment News

Spotlight on Prescription Medication

No Way! A clusterhead's story pt. 2
Creative Corner

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contact us: newsletter@ouch-us.org

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

O.U.C.H. News

The Board of Directors announces the following administrative changes:

- ✦ Michael Berger and Pete Batcheller have resigned from their positions on the Board of Directors and all committees, citing personal and work related changes that would preclude them from giving their positions at OUCH the full attention they deserve. We certainly understand that "real life" and family come first and wish them well.

Tony Amabile has resigned from his position on the Board of Directors and all committees, citing health issues that would hinder his effectiveness at OUCH. We hope that Tony can get his issues resolved and get back to full health soon.

We thank all three departing members for their hard work and dedicated service to OUCH and wish them well in whatever the future holds for them.

- ✦ The Budget Committee now consists of Brian Nemhauser (chair), Jean French, and Mike Day.
- ✦ The Funds Raising Committee is now staffed by Michelle Adamson.



Convention 2008 Update

This message was posted on the OUCH website and on www.clusterheadaches.com on 11/07/2007

2008 OUCH Convention Proposal Deadline Extended

The deadline to submit proposals for the 2008 OUCH Convention has been extended again in an effort to allow as many people to participate as possible.

For more information, check out the Convention & Gatherings Page at:

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

and see the announcement at:

<http://www.ouch-us.org/announcements/convention08.html>

This link contains contact addresses and forms to assist you in making your proposals.

We will be happy to answer any questions you may have. Please send your proposals and any questions to convention@ouch-us.org, no later than November 15, 2007.

2nd Annual Supporter Appreciation Day

- November 15, 2007 -

Sometimes, we as cluster headache sufferers can get so caught up our own world of pain that we forget to say thank you to those who support us.

Supporters are those special people who help us through our attacks, round up our meds, shuffle the kids off to another room so they don't see us in such a terrible state, advocate for us with our doctors, fight with the insurance companies, make excuses to our friends and family when we have to cancel outings and gatherings, comfort us when we are down and kick us in the pants when our pity party goes on a little too long. Worst of all, they have to sit helplessly by knowing there is nothing they can do to stop the pain.

OUCH knows how much supporters do for sufferers, so we have set November 15 aside as Supporter Appreciation Day. This is a day for all cluster headache sufferers to do what we should be doing every day; recognizing and thanking the most important people in our lives - YOU who support us.

OUCH set up a special page where clusterheads everywhere can leave messages for those who mean the most to them. To read those messages or to leave one of your own for your special supporter, please visit: <http://www.ouch-us.org/suptapprday.htm>

We would also like to announce the winner of the Supporter Appreciation Day Slogan Contest. This year's winner was: Bill Mitchell with the winning slogan:

"Supporters are our true CHampions"

Bill will be able to choose one supporter who will receive a box of chocolates donated by our own Helen "LeLimey" Williams.

We thank everyone who participated and urge all clusterheads everywhere to make every day Supporter Appreciation Day!



Announcements



Welcome to our New Members!

The past month saw 39 new members join our ranks.

New York - 3	Missouri - 1	Maryland - 1
Florida - 3	Nevada - 1	New Jersey - 1
Arizona - 1	Pennsylvania - 1	Kansas - 2
Connecticut - 1	California - 3	Louisiana - 1
Texas - 2	Idaho - 1	Maine - 1
Illinois - 3	Michigan - 1	England - 4
Montana - 1	Hawaii - 1	Canada - 3
Tennessee - 1	Ohio - 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!



Welcome New Team Members!

We are pleased to welcome two new additions to the Newsletter Team - Dennis McCracken and Barry T. Coles. We would like to be the first to say thanks to these two for stepping up to help their fellow sufferers.

THE OUCH STORE IS OPEN!

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





BREAKING NEWS!!!!



OUCH Hit by Wedding Bells!

Dave, more commonly known to us all as “Dape” has proposed to his partner and supporter Julie and she has very graciously said Yes!



The happy couple and their gorgeous daughter Kayleigh.



Joshua

Dape is a helpline advisor for OUCH UK and does as much as he can for other ch’ers. He’s always on the end of a phone, as is Julie, whenever I need them and I couldn’t be happier for them.

I’m sure you’ll all join with me in wishing them every happiness life can offer.

Helen Williams (also known as Dapes little sister!)

From the Supporter Message Page:

JULIE

No words i could write would ever be enough after what you have done for me.

I love you with all my heart, body & soul and i want to be with you for the rest of my life so..... WILL YOU MARRY ME

Yes i know you have already said yes but i want to get married sooner rather than later so lets just do it, forget the aunts, uncles, cousins and the rest, we are the ones that matter. Please say yes and make me the happiest man alive.





More Messages to Supporters from Clusterheads:

To the Queen of hearts. You nagged me until I finally went to the doctor and stopped trying to gut my way through it alone. You found the web site that changed my life and forever changed how I attacked CH. You've brought me ice packs, oxygen tanks, Imitrex jabs, cafergot, and kept the poor kids away when they were little. You've endured the meet and greets and conventions, you've tolerated all of this for over 27 years.

Any men would consider himself blessed to call you his supporter, I get to call you my wife too! Thanks for taking the "for better or worse" so seriously!!!!

Joe

T,
You have stood beside me, never waivering, through headache after headache after headache. When I thought that I couldn't live through another one, you encouraged me, rubbed my neck, let me squeeze your hand until I thought I would break it and put up with many sleepless nights! I know that I could not live the quality life that I live, without you! From the bottom of my heart, thank you for being true to the vows we took 17 years ago, "in sickness and in health!" I'm so sorry you have had to go through this but I hope you know how deeply I am indebted to you for all you do for me when I have a headache. I (love) U!!!!!!!!!!!!!!!!!!!!!!!!!!!!

Lisa

Shannon

Thanks for always being there for me with and without the headaches! I know I'm sometimes as big of a pain in your but as they are in my head.

And thanks to DJ and the rest of you as well. You've saved and comforted many lives!

Treatment News

Spotlight on Prescription Medications

by Dennis McCracken

Dihydroergotamine (DHE)

Ergot alkaloids are among the oldest drugs used to treat migraine and cluster headaches. While they have been largely replaced in acute treatment of cluster headache by Triptans, they remain an effective treatment in situations where patients have exhausted other mainline treatments and really need a break. DHE is used to treat both chronic and episodic CH types though the statistics show the drug is more successful with episodic CH than chronic.

Dihydroergotamine (DHE) is the drug Ergotamine hydrogenated and is sold under the brand names *D.H.E. 45*. DHE acts as a serotonin antagonist and is a powerful vasoconstrictor.

In an article published in the journal *Headache* 2004 Mar;44(3):249-55 outpatient DHE therapy was studied. The results after 1 month following treatment are summarized below.

	Complete Relief	Partial Relief	No Relief
Total Patients (97)	61 (63%)	13 (15%)	23 (24%)
Episodic (60)	44 (73%)	9 (13%)	7 (12%)
Chronic (37)	17 (46%)	4 (11%)	16 (43%)

DHE is administered through injections in both inpatient and outpatient settings. Outpatient treatment can be done in a doctor's office, ER or clinic. It just has to be done somewhere IVs can be handled safely. The drug is injected 1mg at a time with a limit of 3 doses in 24 hours for a total of 9 doses over 3 days. When done outpatient, two trips a day are required to see a nurse or Doctor for the first two injections. The patient must self administer the third dose at home through subcutaneous or intramuscular injection. Some protocols also call for the use of Migranal nasal spray for the third dose instead of DHE-45. Typically the drug metoclopramide (brand name Reglan) or Phenegan is also administered to counteract nausea, a very common side effect. The 1mg IV push should be done very slowly over 10 minutes to avoid a severe burning sensation.

All triptans such as Imitrex, Zomig, Axert, Amerge, Frova, Relpax, Maxalt and ergot containing medications such as methysergide should not be used within 24 hours of beginning DHE treatment.

DHE 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.

Because DHE is such a powerful vasoconstrictor, it should not be administered to anyone with a heart condition or coronary or peripheral artery disease, uncontrolled high blood pressure, previous hypersensitivity to ergot alkaloids, recent vascular surgery, sepsis, severely impaired liver or kidney function or nursing mothers.

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If your Doctor suspects that your vascular system is not up to the treatment he or she should order a vascular study before proceeding. There is a long list of rare but possibly fatal side effects including heart attack, cerebral hemorrhage, stroke, transient ischemic attack (TIA) and cyanosis of the fingers and toes which may result in gangrene. In addition patients may experience nausea, muscle pains, numbness and coldness.

The treatment can be rough with venous bruising creating soreness in the limbs which can last for days following treatment. This condition can be somewhat alleviated with warm compresses. Also, if being treated outpatient, you may not feel well enough to driving yourself in after a dose or two. It would be a good idea to have someone available to take care of the driving should this happen.

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>

No Way (The adventures of an agoraphobic clusterhead)

by Anthony Amabile

Part II

After two hours my suitcases were repacked and I was satisfied I'd be prepared for any eventuality; famine, flood, earthquake, heat wave, draught, blizzard, tsunami, sand storm, ice age, nicotine fits and Kip 10s.

The last item on my disaster chart (the Kip 10s) inspired the most dread. I had only one pack of Trex jabs with me and a few q-tips to ration four, half doses out of them. My thoughts began to race again - "What if I get hit on take off and while I'm dividing the injection with the q-tip a paranoid passenger screams for security? What if.... "Stop!"
It's time to leave for the airport... I can obsess on the way there.

My mind was swept along during the ride to the airport on a raging river of "what ifs" and "should haves" and I was a bit startled to finally find myself at the check in curb. No tires exploded and no toll booths had tipped. The chit chat Ben and I had along the way was managed by the part of my brain that handled such matters as breathing and heart beat. After 12 years of being together, detached chit chat is forgivable but not always desirable. As we unloaded the baggage from the car and screamed our goodbyes I felt the pangs of anxiety closing in as part of my comfort zone was about to drive away. My chest tightened and my heart began to pound as another wave of terror began to consume me.

"Stay focused! Use the tunnel!" I learned long before, that if I used tunnel vision to navigate through such places it somehow helps me to feel less vulnerable. I quickly scanned the inside of the airport for the check-in counter and remained focused on the destination point, everything in my peripheral vision becomes like matted padding. I felt my face ache from the stiff mask of a smile I wear for such an occasion. The weight of the two large suitcases and one carry on helped me to stay anchored as I managed to juggle them without tipping over. Check-in complete, baggage unloaded, I made another visual tunnel to my next destination. I felt like a mole.

As I moved along with a swift stride toward security I began the "airport strip tease" Soon everything went into my carry on leaving me wearing only my shirt and a pair of shorts my boarding pass and ID were clenched in my teeth during the ritual and I have to laugh thinking of how odd that must have looked. The dreaded thought then occurred to me... "You're drawing attention to yourself! Stop it! Security will detain you and you'll miss your flight How will you make it to Newark? I tried to look "normal" but the harder I tried the redder my face became. My face felt was hot and my ears felt as though they would burst into flames. Breathing was an effort and I began to get nauseous. I wonder what Lutefisk will taste like when I get to Norway?

(to be continued...)

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.



Creative Corner

Cluster Headache

by Frank Weeden

I wish I didn't exist
I don't want more pills to pop
There's a brain-crash in my eye
And I can't make it stop
Screams me awake at night
Fades out all my days
And it dogs my heels and makes me feel like
blowin' myself away

Another cluster headache!
Count the minutes through the pain
Cluster headache!
A world war inside my brain
Cluster headache!
Suffer thrash and cry
Another cluster headache!
God please just let me die...

Pull myself along
Through another cardboard day
Everything is so surreal
Two dimensional and gray
Hammer hanging overhead
Just wait for it to fall
Like waiting to be shot at dawn as the demon
start to crawl

Another cluster headache!
Curse the minutes through the pain
Cluster headache!
Super nova in my brain
Cluster headache!
There's no remedy left to try
Another cluster headache!
God please just let me die...

There's nothing left but an empty shell
There's nothing left but another hell
There's nothing left but to reel and fall
There's nothing left. I'm a broken doll

I wish I didn't exist
I don't want more pills to pop
There's a brain-crash in my eye
And I can't make it stop
Screams me awake at night
Fades out all my days
And it dogs my heels and makes me feel
like blowin' myself away

Another cluster headache!
Count the minutes through the pain
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