

The O.U.C.H. Newsletter

March 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 O.U.C.H.

The past month saw 26 new members

- | | |
|----------------------|------------------|
| 1 from Kentucky | 2 from Australia |
| 1 from Indiana | 2 from England |
| 1 from Arkansas | 1 from Holland |
| 1 from Montana | 2 from Canada |
| 1 from New York | 1 from Germany |
| 2 from Pennsylvania | 1 from Argentina |
| 1 from Massachusetts | 1 from Mexico |
| 3 from Ohio | |
| 2 from California | |
| 1 from Iowa | |
| 1 from Connecticut | |
| 1 from Virginia | |

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



Farewell Mike

OUCH is sad to announce that Mike Day, OUCH Vice President, has reluctantly tendered his resignation for health reasons. *"I don't want to just be 'on the Board,'"* said Mike. *"That wouldn't be fair to the membership or to my fellow Directors and Officers. Because I can't be a productive member right now, I am stepping aside to let someone else step up who can help further the goals of the organization."* We wish Mike well in both his health and his future endeavors.

Announcements

OUCH Convention News

The 2007 OUCH Convention will be held July 12-14, 2007 in Richmond, VA.

The convention hotel is the Doubletree Hotel at Richmond Airport, 5501 Eubank Road, Sandston, Virginia.

Hotel registration is now open. The group name is OUCH. There is no online registration for groups. To register, please call the hotel directly at 804-226-6400 or call the toll free group reservation number at 800-422-0933.

Rooms will be \$89.00 per night. This group rate will be available until June 12, 2007. Hotel registrations received after June 12, 2007 will be at their normal rates.

Convention registration fees have not been set, yet, but registration for the entire convention includes:

- * All Technical Sessions
- * Dinner of Friday
- * Breakfast, Lunch and Dinner on Saturday
- * Entertainment and Auction on Saturday
- * Convention T-Shirt
- * Goodie Bag with O.U.C.H. and other items

Banquet Only registration includes:

- * Dinner on Saturday,
- * Entertainment and Auction on Saturday
- * Convention T-Shirt

For updated information check out the RichCon webpage at:

<http://www.ouch-us.org/gatherings/richcon07/richcon07.htm>



If you would like for your doctor to receive an invitation from OUCH to attend this year's convention, send his or her name and address to:
richconinvites@ouch-us.org

Announcements

GlaxoSmithKline Class Action Settlement Information

There is a Proposed Settlement with GlaxoSmithKline (GSK), one of the Defendants in a class action lawsuit pending in the U.S. District Court for the District of Massachusetts. The name of the lawsuit is In re: Pharmaceutical Average Wholesale Price Litigation, Docket No. 01-CV-12257-PBS, MDL No. 1456.

The lawsuit claims that certain drug companies reported false and inflated average wholesale prices (AWP) for certain types of outpatient drugs. The reported AWP's are often used to set prescription drug prices that are paid by Medicare, consumers and insurers. The lawsuit asks the Court to award money damages to some people who paid or made co-payments for the drug. This Class Action would apply to you:
If You Made or Are Obligated to Make a Percentage Co-Payment
or Full Payment for the GSK Drugs:

Kytril Injectable (Granisetron HCL)
Zofran Injectable (Ondansetron HCL)
Alkeran (Melphanan)
Kytril Tablets (Granisetron HCL)
Myleran (Busulfan)
Retrovir (Zidovudine)
Zofran Orals (Ondansetron HCL)
Zantac (Ranitidine HCL)
Imitrex (Sumatriptan)
Lanoxin (Digoxin)
Navelbine (Vinorelbine Tartrate)
Ventolin (Albuterol) or
Zovirax (Acyclovir)

GSK has agreed to pay \$70 million to settle these and other related claims. A \$4.5 million payment to certain State Attorneys General, as well as attorneys' fees and the costs of administering the Proposed Settlement, will be deducted from the Settlement Fund before distributions to Class Members.

The remaining fund will be distributed to consumers and insurer Class Members (including Third-Party Payors) who submit a valid claim.

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Announcements

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GSK denies any wrongdoing. The Proposed Settlement is not an admission of wrongdoing or an indication that any law was violated. GSK has entered into the Proposed Settlement solely to avoid further expense, inconvenience, and the burden of these litigations and any other present or future litigation arising out of the facts that allegedly gave rise to these litigations. GSK also wishes to avoid the distractions and diversion of their personnel and resources, and thereby to put to rest this controversy and to avoid the risks inherent in uncertain complex litigation.

For additional information and answers to frequently asked questions. Please refer to:
http://www.gsksettlement.com/glaxo/consumer_en/FAQs.htm

Remember, there are deadlines which you will need to meet if you choose to become a part of this class action.

Due Date for Filing a Claim: Postmarked on or before May 28, 2007

Due Date for Request for Exclusion form: Received no later than May 27, 2007

We will keep you updated on any future developments via the newsletter.

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>

Community News

California here I come!

Exciting news from the Neuro News newsletter – Professor Peter Goadsby and his team of Manjit Matharu and Jim Nagy will be moving to UCSF in October.

Jim Nagy and Manjit Matharu have been clinical fellows with him at the Institute of Neurology in Queens Square, London and they have been invited to establish a migraine programme with a clinic at Mt Zion and a research laboratory at Parnassus with another following at Mission Bay.

It is unclear at this point in time whether he will be seeing Cluster Headache Sufferers as patients but we will report on this as soon as possible.

If anyone would like to read the full article it can be viewed here:

<http://www.ucsf.edu/brain/pdf/NeuroNews.pdf>



Clusterville Birthdays!

We celebrated some birthdays this month and you know what? The poor old newsletter team didn't get a single bit of cake!

Just to let you know there's no hard feelings we'd like to send you whizzing towards your next birthday with a huge Many Happy Returns from us!

Terry (Gore2424) Jan 20th

Linda Rambow Jan 28th

Linda Howell Jan 29th

Tony (Artonio7) Feb 1st (pinch and a punch for you little boy!!)

Cat Lind Feb 6th

Ben (Tony's supporter) Feb 7th

Andrea (Broomhilda) Feb 9th

Patti (Peppermint) Feb 9th

Chuck Feb 14th – The Cupid of OUCH!

Community News

Clusterheads Invade Iowa - A look at DavCon IV

Once again the Best Western Steeplegate Inn in Davenport, Iowa played host to the largest Cluster Headache meet and greet outside of an OUCH convention.

On January 25, 2007 Clusterheads from as far away as Texas, Delaware, Virginia, and North Carolina joined their Midwest brethren for a weekend of fun and good times.

Gathering in the hotel atrium sufferers and supporters alike socialized for 3 days. Many attendees also enjoyed trips to local casinos, restaurants, and other local attractions such as the John Deere Museum.

Clusterheads in the atrium:



One fun tradition at DavCon is outrageous footwear. This year's "winner" was Roy, son and supporter to Bill.

Local resident, expert model maker, and Clusterhead Terry Gordon brought his latest creation "The Beast Hunter" for everyone to enjoy. On Saturday night, Terry presented the Beast Hunter to DJ (founder of clusterheadaches.com) and his wife Steph as a token of his appreciation for all they have done for the Cluster Headache community.



Saturday night also brought the DavCon cake....

...and a very special gift. Supporter Raye brought a custom made DavCon jacket to give away to a lucky attendee.

The lucky winner was Sue....



Understand that DavCon is but one of the many Meet and Greets held through out the world. For those that have never experienced meeting others that suffer and support, please make plans to attend a Meet and Greet near you. You won't regret it.

Plans are already under way for DavCon in January2008. Watch the Meet and Greet section of clusterheadaches.com for details.



Clusterheads Around the World...

Meet Melissa K. Filtz

Name : Melissa K. Filtz

Age : 32

Where do you live : Wittenberg, WI

How long did you have CH before you were diagnosed : 8 years

How long have you had CH in total : 16 years

Do any other family members have CH to your knowledge : no

Do you think it took longer to get diagnosed because of where you live : it's possible

Did you have a hard time getting to see a neuro : no

Do you think knowledge of CH is good within the medical community in your country :
Yes, especially to help treat even rarer disorders like SUNCT

What meds are you using or have you tried : My last cycle I used Oxygen and Kudzu root. In previous cycles I've tried Depakote, Imitrex injections and nasal sprays & Amnitryptiline(sp?)

What restrictions are there on meds for you : none

Can you get O2 : Yes

Does your insurance cover all your expenses : No

Regarding insurance (or lack of):

How are your meds paid for : Insurance pays all except a \$10.00 co-pay

How expensive are they? : When I used Imitrex, it cost about \$108 out of pocket for 4 trex vials and 12 nasal sprays under our old policy.

Are there treatments that are not available where you are : not that I know of

Have you tried any alternative therapies and if so was it through choice or necessity :

Yes I have and it was by choice.

What sort of support (or lack of) do you get from:

Your family? Wonderful support from my immediate family. They still cannot understand fully the demand clusters puts on me, but they try their best and that's all I can expect from them.

Your workplace? : I do not work outside the home.

How has it affected your social life? : My social life is almost nil when I'm in cycle.

Where do you get your best mental or emotional support? : My husband and then www.clusterheadaches.com

Is there anything else you'd like to say? : That I accept my condition when it occurs (I'm episodic) and I do not dwell in it or let it control my life. It is a part of who I am and I really do believe I'm a more empathetic person because of it when I'm out of cycle.



Cluster Supporters Around the World... Meet Teresa Verburgt

Name : Teresa Verburgt

Age : 20

Where do you live : Madison, Wisconsin, USA

How long have you been a supporter for someone with CH : since I was born, but I remember actually needing to physically support my mom around 12 or 13

Did your sufferer have CH before you knew them or not : no

How has it affected your family : I think it is one of those things that has brought my Mom and I closer together actually. Most of the time I was the only person there, so I would go get the oxygen tank or get a shot of imitrex ready and give her the shot. Most 12 year olds don't have to go through that. So we would talk about what to do while she wasn't getting hit and that really opened up our communication a lot.

How has it affected: Your social life : There were times where I didn't want to go out with friends because I didn't want to leave her alone. I was scared to practice my trumpet because I didn't want to cause a headache.

Where do you get your best mental or emotional support : From my Mom actually. She does her best after a hit to tell me that what I did helped.

What tips can you give a new supporter : Talk about what your sufferer needs before the fact. And try to stay calm, they will be okay.

What do you do when it gets too much for you : I start to cry and the last time I called my grandparents because I didn't know what else to do. Mom was in a whole lot of pain.

Is there anything else you would like to say : One of the best parts about being a supporter is the chance to meet other sufferers and other supporters and to know that this is just another piece of my life and that it is possible to live.

To contact the Family Services Team go to
<http://www.ouch-us.org/familysvs/familysvs1.shtml>
or e-mail familyservices@ouch-us.org

Spotlight on Prescription Medications

Amitriptyline

“...but I’m not depressed!” Doctors sometimes prescribe medications for their off label properties and effects. Such is the case with Amitriptyline. Amitriptyline is a first generation antidepressant known as a “Tricyclic Antidepressant,” but it is also sometimes prescribed for its ability to help alleviate certain types of nerve pain. It has been shown to be somewhat effective in treating diabetic neuropathy, fibromyalgia and other chronic pain syndromes, including cluster headache.

As with any medication, you should discuss what the medication is supposed to do, how long it should take to start working and any potential side effects with your doctor and your pharmacist. The most common side effects are drowsiness, dizziness, headache, nausea, dry mouth, mild tiredness or weakness, increased appetite or craving for sweets, and weight gain. You should contact your doctor immediately if you experience the following: mood changes, anxiety, panic attacks, trouble sleeping, irritability, agitation, aggressiveness, severe restlessness, mania (mental and/or physical hyperactivity), thoughts of suicide or hurting yourself.

Pregnancy: Amitriptyline is an FDA Category C medication 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.

Lactation: Amitriptyline passes into milk and its use should be avoided during lactation.

Availability: Amitriptyline is available in generic form as well as in several “Name Brand” formulations.



Serotonin Syndrome Warning

Since we are discussing an antidepressant in this issue, it seems appropriate to remind our readers of the July 2006 warning issued by the US Food and Drug Administration stating that using classes of antidepressants called SSRI's (Selective Serotonin Reuptake Inhibitors) or SNRI's (Selective Serotonin/Norepinephrine Reuptake Inhibitors) in combination with Triptans can cause Serotonin Syndrome - a possibly life threatening condition.

Serotonin syndrome occurs when the body has too much serotonin, a chemical found in the nervous system. Serotonin syndrome symptoms may include restlessness, hallucinations, loss of coordination, fast heart beat, rapid changes in blood pressure, increased body temperature, overactive reflexes, nausea, vomiting, and diarrhea. Serotonin syndrome may be more likely to occur when starting or increasing the dose of a triptan, SSRI or SNRI

To read the entire warning go here: http://www.fda.gov/cder/drug/advisory/SSRI_SS200607.htm

Treatment News

Medication Pregnancy Categories

In these prescription medication articles, the medication's "Pregnancy Category" is listed. Many websites list these with varying wording, but the meaning is the same. This list of the US Food and Drug Administration Pregnancy Categories and what they mean was taken from the May - June 2001 issue of the "FDA Consumer" magazine.

Category A - Adequate, well-controlled studies in pregnant women have not shown an increased risk of fetal abnormalities.

Category B - Animal studies have revealed no evidence of harm to the fetus, however, there are no adequate and well-controlled studies in pregnant women.

or

Animal studies have shown an adverse effect, but adequate and well-controlled studies in pregnant women have failed to demonstrate a risk to the fetus.

Category C - Animal studies have shown an adverse effect and there are no adequate and well-controlled studies in pregnant women.

or

No animal studies have been conducted and there are no adequate and well-controlled studies in pregnant women.

Category D - Studies, adequate well-controlled or observational, in pregnant women have demonstrated a risk to the fetus. However, the benefits of therapy may outweigh the potential risk.

Category X - Studies, adequate well-controlled or observational, in animals or pregnant women have demonstrated positive evidence of fetal abnormalities. The use of the product is contraindicated in women who are or may become pregnant.

THE OUCH STORE IS OPEN!
<http://www.ouch-us.org/ouchstore.htm>





Cluster Headache, Dreaming & Neurogenesis

(twelfth in a series)

by Peter May

How Entheogens work and their efficacy in CH

After many years of research, the site of action for entheogenic drugs has now been identified and they are believed to act in the brain at a specific receptor subtype as the previously discussed chemical neurotransmitter – serotonin. However, the understanding of their mechanism for action in cluster headache and other disorders is somewhat limited.

Although a large number of drugs may be considered psychoactive, only a small group are generally identified as hallucinogenic or entheogenic, namely: LSD, LSA, DOM, mescaline, DMT, psilocybin, psilocin, and their congeners. They can all be considered members of the same drug class for two important reasons: firstly they elicit a common set of psychological effects and secondly, these drugs display both tolerance and cross-tolerance (to be discussed later). However, certain molecular differentials do exist: LSD and LSA are classified as ergot derivatives; mescaline and DOM are phenylethylamines; and psilocybin/psilocin and DMT are indoleamines.

Before proceeding further, it may be helpful to once again discuss briefly the events which allow brain cells (neurons) to influence one another. Most neurons in the adult brain communicate chemically. These chemicals (neurotransmitters) are released from the axon terminals of one neuron and cross a small gap (the synaptic cleft) between neurons to form a chemical bond with a protein receptor, producing either excitation or inhibition of the target neuron. If all the inputs to the target neuron combine to produce a sufficient level of excitation at the cell body, the neuron fires or discharges an action potential which propagates down through the axon, repeating the cycle of release of neurotransmitter into the synaptic gap.

I found the following superb analogy which hopefully simplifies the complexity of the workings at the synapse. Consider two train tunnels that do not meet but have an intervening space of, say, 100 feet between the ends of each of them. Furthermore, imagine that a train speeds along one of the tunnels at huge speed. This is akin to the high velocity impulse travelling along a neuron. Not dogged by track problems, this 'Intercity Electrochemical Impulse Express' reaches the end of the tunnel and duly crashes onto specially constructed buffers. The dramatic impact upon the said buffers causes a group of strategically placed gas canisters to explode, thus dispersing their gaseous contents into the gap between the two tunnels. The gases instantaneously diffuse across the gap and cause a reaction to occur to another stationary train situated at the start of the next tunnel. As soon as molecules of the gas reach this next train, a clever reaction occurs in which the engine roars up and the train is off, at the same speed as the first train. Meanwhile the gas molecules in the gap are immediately 'mopped up' (and then conveniently re-cycled) so that they do not cause the replacement train (which magically appears almost instantly to replace the one that just sped off) to start up also. And in the first tunnel the original train has also been removed in order to allow another to follow if needs be.

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One complication of this simple picture of chemical neurotransmission that is of special relevance to entheogens is the fact that each neurotransmitter can act at more than one type of receptor. It is assumed that these receptor subtypes exist for the purpose of diversifying the cellular effects of any given neurotransmitter. For example, serotonin acts at the 5-HT1A, 5HT1B, possibly 5-HT1C, and the 5-HT2 receptor subtypes in the brain. Because the protein molecules, which constitute receptor sites have slightly different conformations for each subtype, drugs can be developed to stimulate (or block) a particular receptor subtype.

So focussing on the historical analysis of entheogens, firstly it was discovered early on that many of them had a molecular structure similar to that of serotonin. Secondly, a series of animal studies examining brain neurochemistry following the administration of hallucinogens invariably reported changes in the levels of serotonin. Finally, data from a variety of different sources led to the conclusion that hallucinogenic drugs exert their critical action at a specific serotonin receptor subtype: 5-HT2. Depending on the particular brain area, the action may be either excitatory or inhibitory. This does not preclude the possible involvement of other neurotransmitters in the action of hallucinogenic drugs; in fact, structural differences in the drug molecules are probably responsible for variations in the phenomenological effects produced by them.

The medicinal efficacy of entheogens in cluster headache, however, still remains largely a mystery. As we have seen, the current understanding of the mechanism of indole ring based entheogens is that when consumed they initially excite serotenergic neurons, specifically the 5-HT2 receptors. Soon afterwards, the number of active 5-HT2 receptors is reduced in the brain. This process can be simplified in the following way: The body maintains stability or homeostasis. Upon the over-activation of 5-HT2 receptors, the body 'decides' to greatly reduce the 5-HT2 activity in order to maintain homeostasis. Soon after dosing, there are fewer 5-HT2 receptors that are able to bind to serotonin which may be one of the reasons CH improves. This process of reducing the number of active 5-HT2 receptors takes about three days (in rats), a similar time frame for which it usually takes to see the benefit of a therapeutic dose in sufferers. This theory, however, may be flawed in its simplicity. Unlike other medications, this effect lasts well after the drug has cleared the system and can provide relief for weeks, even months.

One interesting theory posed by a fellow CH sufferer is based upon one of the most widely reported yet least understood subsidiary effect of entheogens – tolerance and cross-tolerance – that is, a decrease of efficacy of one entheogen taken shortly after another. Thus, if a person has a full-blown experience following ingestion of say LSD, the normal entheogenic response to say psilocybin or LSA taken the next day will be dramatically blunted or abolished.

As mentioned, it takes several days for the receptivity of the binding sites to return to their 'pre-dose' state and this effect manifests itself even though all detectable traces of the entheogen have left the bloodstream. This suggests that it's not just a case of the psychedelic molecule hanging around the receptor site for days and days, but that the receptor site has been in some way temporarily altered by the psychedelic experience.

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The precise nature of this alteration was not further hypothesised in great detail but I would suggest that this altered state actually reflects 'plastic' changes within the brain caused through neurogenesis. The hypothesis does further suggest that for the period of time it takes for the tolerance effect to wear off, the synapses are also operating in a slightly different manner than normal in regards to how they react to (or even perhaps generate?) cluster headaches. The evidence for this is the widely-reported phenomenon of CH sufferers whom prior to dosing with entheogens could normally set their watch by the timing and severity of their attacks, but then experience more frequent and/or more severe attacks than usual in the few days after dosing. It was surmised that perhaps the synapses are in a state of confusion. I would suggest that rather than a state of confusion, the brain itself is going through a state of re-programming and re-building, once again through the action of neurogenesis.

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.



Introducing The Family Services Team

Family Services of OUCH-US is here to help all sufferers as well as supporters get through the sometimes chaotic maze of treatment, advice about medications, knowledgeable Neuros, Ins. problems and just plain dealing with this condition that affects most aspects of our lives.

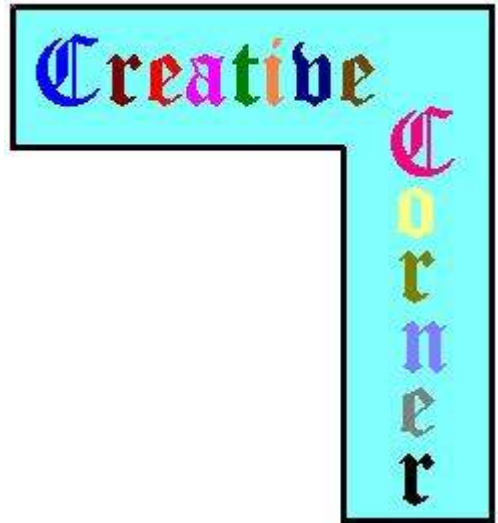
I have built a database of links and info and keep adding to them as I find pertinent items that might help. Even when we don't know the answer to a particular problem, we DO know where to go to research it.

Svenn and I are chronic sufferers who have a great deal of experience and Jackie and Cathi, my other 2 team members have demonstrated time and time again of their ability to listen effectively and to offer wonderful support.

Some people have a need for one-on-one help and don't feel comfortable being on a public message board and we can assure you that when I receive a request for help that each and every person is treated with respect and confidentiality.

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

A poem from Aussie Brian that I'd like
to share with you all.
Thank you Brian, it's very poignant.



Hello old friend

Hello, old friend.
It's been a while
But I see you're back
To sit at my table again.

I barely remember you leaving.
Didn't yearn while you were away.
But here you stand, large as life,
Walked right in and ready to stay.

Maybe I left the door ajar.
Perhaps you felt you were welcome.
So here we are, together again,
Futures entwined, let the music begin.

Let's dance, old friend,
We'll dance to the end.
What merry amusement
We can both share.

They're playing our song,
Just know when it's over,
I'll have led and
You be the loser.

And then it's, so long, old pal.

If anyone else would like to share some of their creativity be it art, poetry or short stories I'd love to print it. We are a talented bunch and it makes me so proud to be able to encapsulate our talents for all to see. Please send any submissions to newsletter@ouch-us.org



A LITTLE BIRD HEARD...

We have a new cook in our midst and not just a chef par excellence but one who gives lessons! Mike Day (AKA Gator or Paw Paw!) had a sumptuous feast courtesy of his 3 year old grand daughter giving his wife, "Grandma Jane" some cooking lesson's on how to make Lasagna! It looked so good there will be no surprises when I report no washing up was necessary as all plates were licked clean! Well Done Sahara, what a good girl you are!

Annette, our very own BB's son Edwyn is a rather special little boy. For Christmas he asked to have help with sponsoring a child in an undeveloped country as one of his presents. He spends a dollar of his lunch money every day to do this and mummy makes up the \$9 difference each month so that he can support his new brother Jeewan in Nepal. Jeewan is nine years old and hasn't been able to go to school as he has had to help support his family since the age of five. Edwyn's money means that not only will Jeewan be able to go to school but his family will be assisted with funds to start farming. Well Done Edwyn, you're a star in my book!

Nani and Margi have given up smoking, please support them all you can because it's a tough thing to do. Ladies I'm proud of you, Margi I hope the Hockey season lasts forever to distract you in the evenings when Princess Savannah is in bed and in the case of Nani – nail down your Cadbury's folks!

Steph, lovingly known as Mrs DeeJ was able to post her sonogram for us all to hear. It was magical and if any of you missed it or (like me!) want to listen again you can do so here <http://www.clusterheadaches.com/heartbeat01.wav>

Mike Day was interviewed a few months back for the local TV news and the report ran in Wichita this month. For anyone who didn't see it you can view it here:

http://www.clusterheadaches.com/video/kake_clusters_high.wmv (High Res)

http://www.clusterheadaches.com/video/kake_clusters_low.wmv (Low Res)

Thank you Mike for getting the message to a wider audience.

We had several mini meet and greets take place this month. First of all Eric (AKA Princess Hannah's daddy who doesn't post enough pic's and EDouble!) Eric went to Boston and made time to meet up with Sean Don and Beth for some of their much boasted about seafood which justly lived up to it's reputation. A great time was had by all and this meet and greet will undoubtedly go down in OUCH history as the one where the natives got lost!

Editor's tip: If visiting Boston be sure and take a street map!

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Beth (Midwestbeth) and Kim (Kimmiedawn) met up in Edwardsville Illinois. It was Beth's first time ever to meet another sufferer and as many of us know, the experience is both indescribable and life changing. If you have never met another ch'er then have a look and see who is in your area and arrange to meet up. I guarantee you'll have the time of your life! Don't forget the OUCH Convention in July too. If meeting one ch'er is incredible then being part of a community where you belong, where everyone understands what you're going through and no one bats an eye beyond making sure you have what you need and getting you a drink when your done! It's the most liberating experience you'll ever have and I so hope I get to meet more of you for the first time as well as all my old friends this year too.

Nani is having sleepover's and we're all invited! Well actually, I think ordered to attend if we're visiting NM is more truthful! Nani had two visits with ch'ers this month the greedy puss! First of all she had Matt and his ever scrumptious dad Craig stop by on their way to CA and as if that wasn't enough she squeezed in a second trip on their way back – some girls have all the luck! Then as if that wasn't enough she also had a visit from Jimi and Ruthie (well you have to put up with Jimi to get to spend time with Ruthie, it's a hardship but she IS worth it!) From the photo's it looks like a great time was had by all and our very own Mooshie is absolutely blossoming too. Don't grow up too fast Mooshie, I LIKE having someone shorter than me!

Brewcrew, also known as Bill (or Wilbur!) is a member of the Empty Suits who we all know and love for the fantastic night we had being entertained by them in Milwaukee. Some of you lucky folks have been able to get along to a couple of their gigs since and I know some of you will be at their gig in Menomonee Falls, WI on the 24th February in aid of 4 Paws for ability, a non profit org that trains service dogs for children with Autism. The aim is to buy a dog for a little girl called Kendall and we'll have a report on how that went in next months issue.

Bill and the lads are holding another benefit for Strides for Lupus which will be on Sat. June 2, 2007, Mark the date in your diaries now folks and more info on the venue and time will be announced when finalised. You'll certainly be in for a good night out cheering on a fellow ch'er, supporting a worthy cause and listening to an AWESOME live band!