



Organization for Understanding
Cluster Headaches

Newsletter September 2005

The Organization for Understanding Cluster Headaches
3225 Winding Way
Round Rock, TX 78664

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 and the advice given here is not meant to replace medical advice from your doctor. See your doctor before attempting any treatment changes.

None of the treatments mentioned in this issue are endorsed by OUCH, the information is presented as a service to it's members.

THE OUCH STORE IS OPEN!



[HTTP://WWW.
CLUSTERHEADACHES.ORG/
STORE_PAYPAL.HTM](http://www.clusterheadaches.org/store_paypal.htm)

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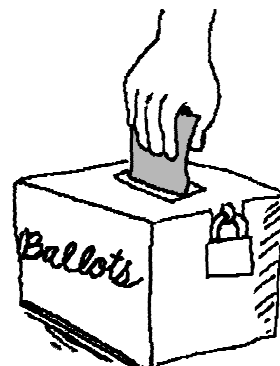
ANNOUNCEMENTS

OUCH sets sail with new crew!
Volunteers are coming out of the
woodwork to help lift that barge and
tote that bail. Please give a big thanks
and a pat on the back to:

Rori Lockman - Fund Raising and
Convention Committee
Elizabeth Goodman - 2006 Convention
Co-Host
Tina Brown - 2006 Convention Co-Host
Matt Matlock - Grants Committee
Melissa Filtz - Membership Committee
Frank Weeden - Media Committee
Anita Wiseman - Newsletter Committee
Hellen Kemp - Newsletter Committee
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BOD Elections

Are coming soon. Look for
announcements to find out
who is running and when to
vote.



OUCH-US has received and accepted an invitation to send a representative to a headache symposium in Oslo, Norway on October 1, 2005.

OUCH's representative, Chuck Setzco will speak on OUCH-US and cluster treatments in the United States. A film taken of Mr. Setzco during a Cluster Headache attack will be shown to symposium attendees and of course Chuck will answer any questions concerning the attack or the film.

Others in attendance and making presentations:

Dr. Inge Monstad, a Professor of Neurology affiliated with both Red Cross Hospital in Oslo and Elverum Hospital. One of the top Neurologists in Norway, Dr. Monstad will speak on Cluster Headaches and CPH.

Dr. Erling Tronvik from the Competence Center for Headaches at St.Olavs Hospital in Trondhiem. Dr. Tronvik is the head scientist in Scandinavia on the Atacand project. He will speak on the Atacand project and new, previously unannounced research project.

OUCH-US views this as a golden opportunity to both educate and foster relationships with the medical community in Scandinavia and is very pleased and honored to take part in this symposium.

Letter from the Editor

Hello! My name is Anita Wiseman and I'm the new editor for your OUCH newsletter. My intention is to keep all of you up to date on the Organization and the pertinent information for dealing with Cluster Headaches.

I am adding a few new Regular Features that will require some member participation. First, I have asked Dr Noah Rosen, from the Jefferson Headache Center to answer member's CH related medical questions. I will add a Children's Corner, where children who suffer or support can add their voices and art. There will be a column where members can ask questions related to Health insurance. Finally, there will be a column devoted to what is happening with CH research.

I plan to include information on all treatments, alternative and traditional, for those interested.

I welcome input, questions, suggestions and ideas.

I look forward to serving the OUCH membership in this capacity.

~Anita Wiseman

Submissions and Letters to the Editor:
contact me at newsletter@ouch-us.org

Letter from the President

Donna Delacerda

Good things are happening for OUCH. Compliance obstacles have now been overcome. Committee Chairs are gathering their staff members and projects being put on the table for discussion. The newsletter is being revitalized. OUCH's future is a bright one, indeed.

I would like to take the time to thank all of the volunteers who are making this revitalization of OUCH possible. I would also like to invite others to join us and take a "hands on" approach to fulfilling the mission and vision statements of OUCH. OUCH needs volunteers to staff the various committees: membership, media, advocacy, and grants.

Help this organization move forward and complete your volunteer application online at:

http://www.clusterheadaches.org/members/volunteer_application.htm

We look forward to working with you.

Donna



*Special thanks to our
sponsors*

Do you have questions regarding your health insurance coverage?

Send questions to:
newsletter@ouch-us.org

Submissions

Submissions for this newsletter should be between 500 and 750 words and related to your experiences with CH and/or treatments. The staff encourages articles and art from children who suffer or support.

Coming soon...

Fresh Research
by Jonathan Byron

Up to date research information on the treatment of Cluster Headaches



Coming soon...

Ask the Doctor
with Noah Rosen MD

Instructor of Neurology, Director of Fellowship Training Program, Co-Clerkship Director for Neurology Jefferson Headache Center Philadelphia, PA

Submit CH related medical questions to Dr Rosen
newsletter@ouch-us.org

Free Online Clusterheadache Book

<http://med-owl.com/clusterheadaches>



Treatment News

Kudzu Being Tested For Cluster Headache Prevention

Kudzu is an invasive plant that has taken over the Southern United States. When used as a supplement, kudzu root has shown to be effective for some in the prevention of CH. It has been used in Chinese medicine for the treatment of migraines, angina, and high blood pressure.

In February, Floridian, a ch.com member posted information about kudzu. He stated that kudzu seems to affect 5ht receptors in the brain, similar to Imitrex and psilocybin. A desperate ch.com member with chronic CH saw this info and decided it was worth testing. Others, both episodic and chronic, followed.

Early testers in both groups reported mostly positive results. Information has been gathered in threads at ch.com and in a free online Cluster Headache Book by Floridian (links at the end of this article). The following is a compilation of info that has been gathered. Disclaimer: Anyone considering this treatment should inform themselves fully and read the links below.

- Kudzu root supplements (both liquid and tablet forms) are available in some health food and vitamin stores and are available online. There are a number of brands and dosages being tested, and there doesn't seem to be any difference in effectiveness. Kudzu starch, commonly sold in health food stores as a food item, should not be used.
- It appears that finding the right dose and timing for an individual may take some time. "Pulsing" seems to be the best way to time doses. The tablets should be taken at least 1 hour prior to the time of day when the most CH activity is present. Once the right times are established, it's important to take the tablets at the same time everyday. Missing a dose can lead to full blown attacks. So far, only 2 testers have reported taking more than the maximum dose recommended on the bottles. It was not working for them in either case, but they did not report any difficulties or side effects. Starting with a low dose and increasing as needed seems to work best. Taking more than the maximum dose is not recommended.
- There is no clear research about taking kudzu with triptans, mushrooms, or common CH prevents. It is not always wise to do so. For example, kudzu has calcium channel blocking properties like Verapamil. If taken at the same time it is possible that blood pressure may drop too low. Some testers have taken both and reported dizziness. Others have taken both with no ill effects. Some testers report that taking Imitrex within a few hours of taking kudzu has rendered the Imitrex ineffective. One tester reports the same results with mushrooms. Two testers may have had interactions with Imitrex that led to serious cardiac complications, but there is no first hand knowledge of the details.
- The most common side effects that testers have reported are: dizziness at first, increased gas and increased bowel movements. One tester had serious bleeding about one month post surgery. The tester didn't begin using kudzu until that time and required additional surgery to stop the bleeding. It is not clear whether kudzu alone caused the bleeding, but caution should be used if one is a "bleeder" or uses blood-thinning meds.

While kudzu is shown to be an effective preventative medication for CH, anyone testing should fully inform themselves of the potential risks. Read the links below and decide for yourself. As stated previously, it doesn't work for everyone, but those that it works for show very promising results.

CH.COM: <http://www.clusterheadaches.com/cgi-bin/yabb/YaBB.cgi?board=meds;action=display;num=1110584362>

Floridians Cluster Headache book: <http://med-owl.com/clusterheadaches/tiki-index.php?page=Kudzu>

(Treatment News continued next page)

Treatment news continued...

A Brief History of a New Treatment

Tom DiStefano

It sounds crazy. These are illegal drugs, the stuff used at raves, wild college campuses and the hippie communes of the '60's. So in 1998 when a fellow called Flash posted on clusterheadaches.com that he planned to "do something horrible" to stop his cluster cycle, there wasn't much positive response to his idea to eat psilocybin mushrooms. That's right, magic mushrooms. Shrooms.

But Flash persisted. Now hundreds have tried his experiment and much has been learned about this crazy notion. It may take as few as two small doses, taken a week apart, to end a cluster cycle or to relieve pain for a chronic sufferer, or it may take weekly doses over a period of months. And the doses do not have to be large - enough to feel like one drank a few beers will do the trick.

A class of chemicals called the indole-ring hallucinogens - psilocybin, LSD, and others less well known - seemed to share this ability to knock out clusters, and it seemed to work for at least 75 percent of clusterheads.

But there are drawbacks. Hallucinogens are not for everyone - those with serious mental problems must avoid them. Some find the experience unpleasant, even disturbing at higher dosages. In order for psilocybin to work well, clusterheads must avoid some of their old standby treatments. Imitrex and other triptans, prednisone, opiate-based pain killers - all seem to interfere with the hallucinogen treatment. Most importantly for some, they are illegal.

Out of discussions on the CH.com message boards, Bob Wold, otherwise known as Pink Floyd, formed a group in August of 2002 called the ClusterBusters to focus on this alternative treatment. In the three years since, the ClusterBusters have found ways the treatment can be effective without the "side effect" of an intense psychedelic experience (or any such experience at all). They identified some of the pharmaceuticals that seemed to block the therapeutic effects, and focused on the treatment that did not interfere. The ClusterBusters determined effective dosing schedules, and found ways to procure hallucinogens without dealing with the criminal underworld.

Science gets interested

Using these reports and discussions, backed by ideas on how the neurochemistry might work and historical research into hallucinogens, the ClusterBusters convinced researchers at Harvard to consider a pilot clinical trial using psilocybin and LSD to treat clusters.

Drs. John Halpern and Andrew Sewell at Harvard's McLean Hospital are reviewing case studies collected by the ClusterBusters and developing a protocol for a clinical trial. If the case study review, due out in late 2005, shows the treatment holds promise, then the hard part begins: getting approval from Harvard's research review board and then multiple agencies with the state and federal governments.

Navigating these agencies won't be easy, but the ClusterBusters found MAPS - the Multidisciplinary Association for Psychedelic Studies - to sponsor the study. MAPS chief Rick Doblin has years of experience in helping research on hallucinogens get off the ground. MAPS is handling the administrative tasks and the finances for the project, and it will take a lot of finances. A small pilot clinical trial is expected to cost between \$250,000 and \$500,000. (continued next page)

Some very generous donations have already been made to support the Harvard study, but much more will be needed if the study proceeds. MAPS is a 501(c)(3) nonprofit and donations are tax deductible. Since MAPS is sponsoring many other projects, benefactors should designate donations for the study on the treatment of cluster headaches. Visit www.maps.org for more information.

The ClusterBusters want to express their appreciation to OUCH-US for the generous donation and the courageous endorsement of research into indole-ring hallucinogen treatment. And we salute our northern friends at OUCH-Canada for opening their discussion boards to the topic.

Seeds of a solution

In the past two years, the ClusterBusters began looking into three different kinds of seeds containing lysergic acid amine - LSA - a milder cousin of LSD. LSA seems to be effective at doses which produce little or no psychedelic effects, and the seeds of the morning glory, Hawaiian baby wood rose and rivea corymbosa are all legal to sell and possess (for gardening purposes only) though they are illegal to consume.

It is still very early in the seed research, but it seems LSA can be effective at doses too small to cause psychedelic side effects. There are also hints LSA works best when taken in sequence with psilocybin - many reported limited relief with psilocybin, which turned into complete relief by following the shrooms with a dose of seeds.

The bad news: morning glory and HBWR seeds contain some unfriendly alkaloids that may cause negative side effects. Rivea corymbosa - called ololiuqui and used for centuries by Central American civilizations - seems to have the least of these unfriendly alkaloids and is the LSA seed of choice so far.

The ClusterBusters put what they learned so far on their web site: check out www.clusterbusters.com/faqlsa.htm and www.clusterbusters.com/lsa.htm

Less is more

ClusterBusters are finding ways to use the treatment without the trip. Some are reporting success by taking very small daily doses of psilocybin or LSA tea. While this doesn't seem to have the success rate of larger, weekly doses, it is ideal for those who don't tolerate the psychedelic effects well.

Then there's the "SPUT" technique - some have found sucking on a Small Piece of mushroom placed Under the Tongue can abort an individual cluster attack without psychedelic effects. Results are variable, and work best at the first sign of attack, but this can be a godsend for the attacks that come between doses.

The ClusterBusters are also learning more about the medications that seem to interfere it seems certain sumatriptan and prednisone will block the treatment, and there are many other suspects. The old standby oxygen works very well - it can help during the "detox" from conventional drugs and to handle the errant attack that often comes after using the treatment.

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ClusterBusters.com update

This web site has actually been around at various addresses since before the ClusterBusters. It has been continually expanded and updated over the years. The latest update to www.clusterbusters.com includes a new page on LSA seeds and a FAQ on using LSA for treatment, plus added and updated information on psilocybin, medication interaction and more.

Research continues into indole-ring hallucinogens and the ClusterBuster site has important surveys for all cluster sufferers - those who have and those who have not tried the ClusterBuster treatments. Please visit and help us beat the Beast.

Bad news in the UK

Psilocybin mushrooms had long been legal in the United Kingdom as long as they were not dried or processed. In the last few years, shops began selling shrooms openly. The backlash came when drug warriors pushed Parliament to rush through a draconian new law that outlaws shrooms in all forms and adds stiff prison terms even for simple possession of what is probably the most innocuous of all hallucinogens, and perhaps the best treatment known for CH.

ClusterBusters in the UK were recently featured in British papers discussing their use of the best treatment they know, and the CB organization is working with UK groups challenging the new law, which went into effect in July. The good news: after a brief flurry of raids on shops selling shrooms, enforcement seems to have been placed on the back burner. Still, we urge our friends in the UK to be very careful.

Albert Hofmann's 100th birthday

Dr. Albert Hofmann turns 100 years old on Jan. 11, 2006. Dr. Hofmann invented LSD in 1943 while looking for a headache treatment, but the uproar over the drug in the 1960's led him to call it "My Problem Child." We hear Dr. Hofmann is very gratified to learn of renewed research, and we hope he stays around to see it come to fruition. To mark his birthday, a symposium on LSD - "Problem Child and Wonder Drug" - is set for Basel, Switzerland Jan. 13 - 15, 2006.

Editor's Note:

MAPS has received a \$5000 donation from the Seattle Foundation to be applied directly to the psilocybin/Cluster Headache reserach fund. The Seattle Foundation is a very prestigious organization that is the largest and oldest community foundation in Washington State.

Visit www.clusterbusters.com for more information on alternative treatments.

OUCH 2005 Convention

O.U.C.H. Convention July 15-17, 2005 – Dallas, TX
Submitted by Bill Mingus

The Organization for Understanding Cluster Headaches held its 2005 Convention at the Crown Plaza Hotel – North in Addison, TX, a suburb of Dallas. The Crowne Plaza provided a great facility to approximately 55 O.U.C.H. members and guests. The Crowne Plaza is a very posh hotel and we gave the staff a lesson in cluster headaches. They witnessed more than a few people getting hit. From the meeting rooms to the bar, the staff was helpful and understanding of our unique medical condition.

Thursday and Friday were scheduled for arrivals, meeting, and greeting and registration. The O.U.C.H. store was officially open for business. With a mix of convention veterans and several convention “newbies” including some from as far away as The United Kingdom, Thursday and Friday were emotional days with people renewing old friendships and making new friends. The saying is true... it feels like you've known each other forever. It's like the CH was beside the point...

Saturday brought the official O.U.C.H. functions. As members filled into the meeting room, Mike Day's informative PowerPoint presentation was available for viewing during the entire day.

Donna Delacerda, OUCH President, opened the meeting and welcomed everyone to Dallas, and the 2005 OUCH Convention.

OUCH Attorney Judith DeBerry spoke and answered questions concerning the new bylaws, and after a short break, members unanimously voted to approve the new bylaws.

After the lunch break, Dr. Noah Rosen, MD, from the Jefferson Headache Clinic in Philadelphia, PA gave a in depth two hour presentation on cluster headaches. Dr. Rosen's associate, med student Brian Melville conducted a study throughout the day investigating the possible connection between allodynia and cluster headaches. Many thanks to all the helped Brian by participating in the study.

Just as Donna Delacerda began her presentation, “Cluster Headache Survival Guide”, she suffered a cluster headache hit and had to cut her talk short. A copy of her PowerPoint presentation is available on cd rom by request.

Saturday night, our banquet consisted of Texas style BBQ dinner, including chicken, beef, and pork, along with all the trimmings. And dessert. It was delicious.

Donna Delacerda presented the following members with OUCH awards. Congratulations everyone!

Lifetime Membership - Jackie Warrior, Svonn Thorn
Supporter of the Year - Eric Diamond, Minnie McConnell
Excellence in Cluster Headache Research - Jonathan Byron
Devotion in Service - Linda Howell
Newcomer of the Year - Chris Manning
Comedic Relief - Randy Jones
Best Liberal in a Supporting Role - Charles Strand
Pay it Forward Award - Elizabeth Goodman
Golden Regulator - Jonny Grasselli

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Our Fundraising and Convention chairperson, Rori Lockman along with Pegg Flick conducted the annual OUCH auction. From original artwork by our fellow sufferers to hand tools, and everything in between, Rori and Pegg raised funds for OUCH while keeping us all entertained. O.U.C.H. made over \$4000.00 from the convention.

Rori was also responsible for a fun game called, "Know your Clusterhead". Modeled after the old TV game show favorite, "The Newlywed Game", 3 pairs of cluster friends answered questions posed by host "Throb Ubrains". Audience applause decided the winners, Frank Weeden and Helen Kemp. Look for "Know Your Clusterhead" to become a convention tradition!

All good things must come to an end, and DalCon '05 was no exception. As in the past, Sunday and Monday were filled with tearful goodbyes. New friends and old alike hugged each other and made their way home much richer for the experience.

Make plans to attend the OUCH 2006 convention in Milwaukee, WI. You won't regret it, we promise.



A Newbie Goes to Dallas, or How I Met My First Clusterheads Submitted by Deborah Hassler

No Longer Alone

Anyone who has Cluster Headache (CH) knows the isolation and misunderstanding that comes with the condition. I have episodic CH that began in 1976, at 16 years old. I went through the usual misdiagnoses and the stigma that sadly too many with CH still experience. I was finally diagnosed at the end of my last cycle in June 1986. Then my headaches just disappeared. Though I completely forgot the word "cluster," I never forgot the hell of those headaches. After an 18 1/2 year remission, I began a new cycle of headaches at 3:30am January 6, 2005.

So much has changed since 1986, triptans are now available to abort headaches, and there are many new medications that see off label use in treating CH. In short, the options for CH treatment have increased significantly. With patience and an open-minded and knowledgeable physician, most people will find a drug cocktail that will bring relief. However, probably the most significant change in the last 18 years is the existence of the Internet. There is an abundance of good (and not so good) information to be found on the net about CH and its treatment. But even more important, I found OUCH and CH.com. The immediate feeling of relief that one is no longer alone, and yes, another human does understand, brings most to tears when they first find these websites. In an instant, a clusterhead's life is forever changed. There is information, advice, support, and an official nonprofit organization (OUCH).

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The Gift

Each year, OUCH hosts a convention that serves as its yearly meeting, and includes OUCH business, a technical program, a banquet, and a chance to meet other people with CH. This year the convention was in Dallas, an easy drive from Houston for me. I had been considering going for months, but was waffling. I was nervous about going alone and nervous because I only knew one person well. I had corresponded with a few others on email and made a few posts on CH.com –but still I worried that I wouldn't find acceptance.

A friend from CH.com insisted I go to Dallas, and convinced me to make the drive. He couldn't have been more right. I was warmly welcomed and immediately felt at ease. There is absolutely nothing like meeting your first clusterhead, much less 45 of them... Nothing! The best way I can describe it is that is like finding your long lost home, a very emotional experience. I understood then what it means when we refer to each other as "family." There is instant acceptance that comes from the understanding of what it really is to live with CH. One doesn't have to explain, anything. We all know, and that knowing creates an instant bond. My only regret is that I didn't have the chance to sit and talk with every person there.

Within the first 30 minutes of my arrival, I saw two people get hit with CH attacks. I was shocked – shocked at the pain, at the intensity, at how frightening it looks from an observer's point of view. Many told me, yes, it is like looking in a mirror. I agree, yet it is more than that. Seeing others go through attacks added wholeness to my understanding of CH. Now I have a concept of CH that is beyond me, something that is more than my own, internal experience. For me, this understanding underscores the seriousness of CH, and makes clear that how important it is to help others, to help OUCH help others. We are the fortunate ones; we have the gift of each other. There are so many more, suffering, undiagnosed, and fighting on their own who need our help.

Taking Care of One Another

One thing that struck me was how perceptive we are when it comes to CH. If someone began showing signs of an impending attack, someone else noticed immediately and was there: "Are you ok? Do you need anything?" This happened again and again. I was out of cycle, but had several phantom attacks while at the convention. All the autonomic symptoms were there, but no pain –no big deal. But someone noticed my droopy eyelid each time, and offered to help. I was amazed that anyone would even notice! If a person just rubbed her eye or neck, someone else was asking about it. When someone did get hit, one person was running for the oxygen tank and another for ice; no one had to be alone if they didn't want to be, not while other clusterheads were near by.



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The Convention

The convention was a huge success. The OUCH officers and many others worked extremely hard, from planning the logistics and the program, to keeping everything running smoothly in Dallas. I truly appreciate everyone's efforts –their hard work gave me the opportunity for an experience I will never forget.

The invited speaker, Dr. Noah Rosen, was a big hit. He is a neurologist/psychiatrist from the **Jefferson Headache Center**. Dr. Rosen is an engaging speaker and gave an informative presentation. He was happy to answer all our questions, but just as important, he asked many questions of us. A physician who cares and is genuinely interested in learning what we know about CH, about how we cope, and which alternative therapies we try and our results, is a very important ally in our fight against CH.

Attending the OUCH convention reinforced my belief in the importance of OUCH and its mission. I think Dr. Rosen was already on our side, but I would bet that after spending a day with us he is now more committed than ever to helping his CH patients and educating his peers. My trip to the OUCH convention has made me think seriously about what I can do to help. My advice to the reader: if you ever have an opportunity to meet another clusterhead or go to an OUCH convention, take it! You won't regret it.



OUCH needs volunteers. Be part of the solution.

Supporters Corner

An Outsider's Viewpoint, and Reason for Being Here

Submitted by Cathi Pierce

Several years ago, by way of the Internet, I was reconnected with an old friend from my school years. It was great! We shared about our present lives, our families and careers, trading stories and how we got to where we are in life. In the course of one of many conversations, my friend threw me a curve ball. I was informed my friend had a rare neurological condition, and by way of explanation, I was directed to CH.com. It took me a few days, but when I did finally arrive in Clusterville. I sat and I read and I cried as I learned how destructive this affliction is, yet, I had never before heard of it! How CH can remove a person from family, friends and take them to the brink of devastation, and tragically, further still. I discovered, as well, people who possess amazing strength, a higher than average level of intelligence, often wonderful sensitivity and an incredible sense of humor. Through my tears, I found myself laughing! That night, I made my entry in the Guest Book. I had found a group of people so fun, so strong and so caring of each other, despite this insidious disease they all suffer, I found I really wanted to know the entire group! I was hooked on Clusterville!

Feeling like I could really DO something about this Beast, I googled, I searched, I researched, yet, I had never seen a hit-had NO clue what they "looked like", but I thought I could understand the agony, the sleep deprivation, the hopelessness, fear The more I read, the more confused I became. I also felt quite foolish and useless. Each time I learned of some new breakthrough, I'd tell my friend. A mistake, indeed, considering CH'ers often know more than their own doctors. Better yet, because one of those break throughs I suggested was a very invasive procedure, which, at best could leave a patient paralyzed ... now, THAT'S help for you! I conjured up jujus, amulets, fervent prayers, looked for boji stones, till I found myself giving up hope. That was when I finally had the opportunity to meet with a sufferer. Just overnight with her not even 24 hrs ... but in this time she was hit several times. I could not believe this is what I had waited for! My night was spent keeping her from damaging her head on the corner of a nightstand. Her night was spent in a world of agonizing pain she worked all night to escape-till it was obvious to me, the beast was letting go of her, and a look of euphoria would fill her face, her toes would uncurl and her body would calm. finally, exhausted, but afraid to lie down. She was embarrassed by what I had seen. I was embarrassed to have invaded her space while she fought so hard ... but glad someone was with her. I looked into her battered face and saw such spirit, huge and unbending. Heartbreaking for the uninitiated? Absolutely! But it was awe inspiring as well. One of my CH friends said to me, in the middle of some nasty bouts, "if it gets worse, I'll just have to dig a little deeper" I wonder if I would have that kind of resolve?

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Coming soon... Children's Corner
By and for children who suffer or support
Submit art and articles to newsletter@ouch-us.org

Despite objection from some, I remain in Clusterville. I have come to care deeply for my friends here. I thought I could leave, but I can't Well, I won't! I've made some lifelong bonds here with some wonderful, witty people. They will ALWAYS be in my heart. Is that because of CH. or despite it? I prefer to think these are people I was destined to meet along my road of life. In Clusterville, I have fallen in love with a little boy who fought a very difficult battle, eventually winning, in a way, since his pain is gone. I have watched as a dear friend's father had a miracle occur, only to die a year later. I have fervently prayed as a son went off to fight in Iraq, and cheered when the news came he was headed home. I continue to get more than I give every day in Clusterville. Daily, I talk to my friends often when one of us needs a boost. I have learned to hear that edge on the phone that says a hit is on its way. I've been taught how to talk someone through the use of O2, so it is effective ... I can sit quietly, swallow my own pain, knowing one of these people I care for is alone in hell at some point, and I try so hard to be there when they are ready to see a friendly face. All I know is these are my friends. I will do whatever I can, whether it is CH related, or life. I have given up on trying to be the one to find a cure. I know I am mortal, but I can continue to read and hope and pray.

I'm not your normal kind of supporter, and because of that, people might be wary of me. NO ONE really needs to live the desperation, the pain, the agony CH deals in order to want to be a help ... even a small help. Anyone would do what they can for a friend - at least that's how I see it.

Sometimes, my husband thinks I'm a loon Come to think of it, he might be right, but not when it comes to my CH friends ... He now knows who these key players are, and he knows if someone is having a particularly bad day - or siege. I am on the phone with my friend, laughing and joking through the good parts, sometimes, silently, listening to be sure they are safe when they drop the phone as a hit comes on hard and fast.

I watch the medical board, but rarely participate. I was quite excited about Kudzu. Now, the jury is still out, since several of my chronic friends are getting nowhere fast with it. I follow the shroom threads. Now I am looking to LSA ... I'm grasping at anything here ... anything that will help Clusterville be pain-free. I want CH to be recognized as an illness that needs more research. I want a sufferer to have respect in an ER, or better yet, I want NO sufferer to ever again NEED the ER due to CH. I want more and more and more people to know about CH. I want them to help with research, donate funds, contribute for research, because, what I want, more than anything, is to know there is SOMETHING out there which can control this monster, and allows my friends to be pain free.

A week or so ago....one of the East Coast CHers came to the West Coast. We got the chance to gather with some other sufferers and supporters and we had lunch in a lovely restaurant at the train station. Some of us had never met, but, funny, isn't it? ... There was not a stranger in the bunch.

One of my new friends commented she had gotten her O2, but didn't have that "special mask" ... Typical of a Clusterhead gathering, one flew out and landed in her lap - somehow, I knew that was going to happen. it always does.

For all the destruction CH can bring, I have seen how, as we all band together, this affliction called CH only creates more bonds And those bonds are what hold friends together when they are in a time of need.