

# O.U.C.H.

Organization for Understanding Cluster Headaches

# NEWS LETTER

December 2003 No.5

## ELECTION RESULTS

### OUCH Election Results

By Donna Delacerda

The votes are in and the results are final. The members of OUCH have elected their officers and members of the Board of Directors for 2004. The new officials start their terms of office beginning January 1, 2004.

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### OUCH Advocacy Team

By Chris Kelly

The **OUCH Advocacy Team** was established after the convention in 2003 to develop and implement communication and educational strategies to inform doctors, insurance companies, and the general public about the unique needs of cluster headache sufferers. One visit to the message boards at [www.clusterheadaches.com](http://www.clusterheadaches.com) shows that many sufferers struggle with misinformed physicians, unsympathetic work environments, hostile insurance companies and an age old stereotype of the middle age, smoker, alcoholic male that has been found to be false. The Advocacy Team's work is vital to providing greater understanding and partnerships with healthcare professionals and related organizations.

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### OUCH FUNDRAISING

By Tara Ann King

The fundraising efforts for OUCH are in full swing. As of October 30, 2003, \$790.01 has been collected through various fundraisers, including the sale of raffle tickets and items sold through on-line auctions. Several holiday related fundraisers are showing promise of greatly increasing this amount.

There have been many items donated for auction in a continuing effort to raise money to help fund the organization. Many of the items donated were hand made by cluster headache sufferers and supporters. Examples of these items are an adorable hand painted angel and a lighter with OUCH engraved on the cover. Currently there is a quilt being made specifically for auction. Also available are hand painted, customized Christmas ornaments.

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### Cluster Club Meeting Results in Important Contacts for OUCH

In September of 2003, President Don Young, traveled to Rome, Italy to represent OUCH-USA at the "Cluster Club Meeting" of the XI Congress of the International Headache Society. Also in attendance were Riccardo Pentenaro (OUCH-Italy), Cris Wallace (OUCH-UK), Carmen Menor de las Casas (OUCH-Spain) and Ete (OUCH-Germany). This year's conference was held at the Ambasciatory Palace Hotel. The Cluster Club was reactivated after many years of dormancy and set historical precedence, as this was the first conference to which a lay organization (OUCH) was invited to participate. The invitation to attend was extended by Dr. G. Nappi (Italy) and sponsorship was provided by Dr. P.J. Goadsby (UK).

"All five national chapters of OUCH were presented to the Cluster Club, an organization comprised of the most esteemed headache research scientists and neurological physicians in the world" Mr. Young stated about this historic event. He added, "My initial feeling was that I would need to press the medical professionals into dialogue...What I discovered was that these highly esteemed professionals sought out the members of OUCH for introductions and dialogue. The reception extended to OUCH was one of friendship and genuine appreciation for our presence."

Physicians from around the world lectured on the topic of cluster headaches. Providing information that included, but was not limited to, epidemiology, classification and treatment of cluster headaches. Our current association with NECH (New England Center for Headaches) and Dr. F. D. Sheftell is one of the positive results from Mr. Young's attendance at this conference. A second important contact, Joanna Kempner, PhD candidate in the Department of Sociology at the University of Pennsylvania, will be writing a dissertation (another first) using the membership of OUCH and cluster headaches as her subjects. Invitations have already been extended to OUCH to attend the next meeting of the Cluster Club.

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## Want to meet other Clusterheads?

By Barbara D. Henderson

Over the last year the Meet and Greet has become the new "in thing" for OUCH members. It provides opportunities for everyone to "meet" others who suffer from cluster headaches. These meetings are usually informal and offer guaranteed fun for all who attend. Never has anyone said they didn't have fun. The apprehension of attending your "first" Meet and Greet is natural—but be brave—It is an experience you will not regret for one moment.

It is a time to be with people who understand when you have to leave the room, and are sympathetic when you return. They KNOW what you are talking about when you say "cycle", "hit" and "dance with the devil". They can laugh with you when you tell the horror stories of your encounters with others who do not understand the pain of cluster headaches.

If you are interested in attending one of these "Meet and Greet" events refer to the calendar of events listed here or access the information through our website <http://www.clusterheadaches.org>

## We Had a Meeting...

Posted at <http://www.clusterheadaches.com/>  
On October 29<sup>th</sup> 2003, 12:43pm

It was so good to meet five other Cluster Sufferers last night at our first "Cluster Sufferer" Las Vegas meeting. We all introduced ourselves, discussed preventative and abortive meds, local doctors, discussion of hypothalamus gland and trigeminal nerve, triggers, potentially forming a local chapter of OUCH, exchanged phone numbers, a demo of the "Imitrex Tip", etc. Met for two and one half hours.

All six of us were male, four out of six are smokers, we are all over-thinkers, we all are left sided sufferers, ages ranged from 32 to 56, five of us are episodic, one was chronic, we all have health insurance or VA medical assistance, two of the six are Vietnam Veterans, three of us are self employed, one service-related disabled and two are full time employees, two reported deviated septum's on the left (Cluster) side—one of these two men had it fixed but did not cure CH's, one had a brain tumor removed-but did not cure CH's, one with history of two closed head injuries. Of the six of us, one has been PF for 4 days, one is chronic with an average of 1 or 2 daily, the other four haven't experienced a CH in 2, 3 and 4 years, respectively. Reported initial onset of CH's began at age 11, 16, 24, 30 and mid-20's, mid-30's. Very productive first meeting with all of us understanding that we now have local contacts and are not alone...

—Gregg in Las Vegas

## Calendar of Events



### January 10-11, 2004

Midwest Meet and Greet  
Steeple Gate Inn—Davenport, Iowa  
Reserve Rooms by Dec 15, 2003  
1-800-373-6900

### January 31, 2004

Raleigh North Carolina Meet and Greet  
debbie4278@yahoo.com Email for Info.

### July 16-18, 2004

2004 OUCH National Convention  
Nashville, Tenn.  
[www.clusterheadaches.org/conventions/2004/index.htm](http://www.clusterheadaches.org/conventions/2004/index.htm)

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*"I could never say in the morning, 'I have a headache and cannot do thus and so'. Headache or no headache, thus and so had to be done."*  
— Eleanor Roosevelt



## From the Editor: Focus on Freedom

By Donna Delacerda

It is ironic that I waited until the last possible moment to put these thoughts into words. Had I done so, even one-day prior, this introduction would read completely different. What difference does one day make? I'll tell you—Saddam Hussein was taken into custody today. Our relentless pursuit of this tyrannical leader

drove this once powerful man into a hole in the ground to hide like a coward. Although the war on terrorism is far from being over, we have captured one of the bad

guys. I think that there are hearts swelled with American pride all over the world today. Score one for the good guys. Congratulations are due on a job well done. For me, his capture reinforces my reasoning in selecting this subject as a feature topic.

***They are our sons and daughters, husbands and wives, fathers and mothers, sisters and brothers.***

There are more than just a few members of our organization who serve or who have family serving in the United States Armed Forces. They are our sons and daughters, husbands and wives, fathers and mothers, sisters and brothers. Each selflessly volunteering to protect our country and its citizens, our ideals and our freedom. In this issue I have chosen to highlight two of our fellow cluster headache sufferers. One, a young serviceman preparing to deploy to Iraq, and the other, a mother whose son has been serving our country, away

from his family for almost a full year. While some may not support our government's involvement in the ongoing fight against terrorism, I have little doubt that anyone will fail to see what outstanding examples of patriotism these two people truly are. Without further adieu...

four years has been chronic. A registered nurse, Nancy recently changed jobs to work with Veterans who suffer from Alzheimer's disease. "I needed to be a part of our military and give something back." Said Nancy of her decision to change jobs. "I never told anyone here" Nancy also stated. "It was something I felt I had to do".

Nancy and her daughter in law, Ali, also raised enough money to send care packages to an entire unit of soldiers from Kentucky that was being deployed to Iraq. Soliciting funds from co-

## Nancy Collins

by Donna Delacerda

Recently featured as Top Military Family on Fox News in Columbia, South Carolina, Nancy Collins (Nancyc) is a shining example of dedication and patriotism. Interviews with Nancy and her family were shown for several weeks every night after the evening news. We are featuring her here in honor of her hard work and dedication.

Nancy is a longtime sufferer from Cluster Headaches. She was episodic for 24 years and for the last

## Jason Aubin

by Donna Delacerda

We recently waved goodbye to Jason Aubin (Samurai), a private in the Army National Guard, leaving for training before being deployed to Iraq. Jason, an episodic cluster headache sufferer for the last 10 years, is a member of the 3rd Platoon, 1st Battalion, 161st Infantry Regiment; a part of Washington's 81st Mechanized Brigade.

He is no stranger to the military lifestyle. "I learned discipline very early on," Jason stated. His mother, Kendra Williams, is a Registered Nurse working for the U.S. Navy and his father, Norman Aubin, is a program manager for software engineering at Boeing Military. Born in Bremerton's Naval Hospital, the military has been a part of Jason's life for as long as he can remember.

When asked about his chosen career, Jason replied "I would

like to go through Ranger training and eventually Special Forces. I would also like to continue with school and perhaps take a commission as an officer." Jason graduated as Honor Graduate from the training academy in Georgia and scored a 92% score on his ASVAB (Armed Services Vocational Aptitude Battery). "I am hoping that my test scores will allow me to choose which ever path interests me."

Jason is also an accomplished Martial Artist. He has been studying the arts since he was 15 years old (he is now 27). I started training in Karate then I trained on my own, learning Greco-Roman wrestling, Jujutsu and some kickboxing. At age 20 I took some Tai-Chi lessons. That started me thinking about the arts in a new way. Once I discovered Aikido, I knew that I had 'come home'. When asked if the Martial Arts helped him in dealing with his CH, Jason replied, "After I be-

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workers and friends, Nancy and her daughter in law purchased supplies, snacks, razors and other items in an effort to provide some of the "creature comforts" to our young men and women overseas.

Why is Nancy so involved? Nancy has been supporting her daughter in law and her grandson Tristan for the last year while her son, Stephen, serves our country in the U.S. military. A devoted mother and grandmother, Nancy has selflessly helped not only her family but has recently brought to us the Adopt a Soldier Program.

A program designed to match soldiers with people who want to send items to soldiers fighting the war on terrorism. Anyone interested in this program please see [www.OPERATIONAC.com](http://www.OPERATIONAC.com) for details. We salute you Nancy for a job more than well done.

***"Do not undervalue the headache. While it is at its sharpest it seems a bad investment; but when relief begins, the unexpired remainder is worth \$4 a minute."***  
— Mark Twain

## E-MAIL TARGETS

By Donna Delacerda

Everyone can help to spread the word about cluster headaches. Each week an "E-Mail Target" is posted on the message board at [www.Clusterheadaches.com](http://www.Clusterheadaches.com). It is a specific person, television program, politician, or medical facility that we are "targeting" that week. In order to gain exposure for cluster headaches, participation is needed from every sufferer and supporter.

Cluster headaches are a rare and debilitating disorder, affecting only a small percentage of the world population. Because of its rarity it receives very little media exposure. In the opinion of some, we are not a "large enough audience". This is why we need to speak out in large numbers. It will take a group effort to prove that there is an audience that is interested in seeing programs about cluster headaches. By focusing our combined efforts on a specific target, we have a better chance of getting media attention.

We recommend clicking on the link provided in the post, and submitting your story or story idea for consideration. This is an easy way for everyone to participate in a way that does not consume a lot of time. Send your E-mail today!

Here are some of our previous targets.

Senator Fritz Hollings-Senate Commerce Committee Chair  
<http://www.senate.gov/~hollings/contact/Webform.cfm>

Dateline-Stone Phillips  
mailto:dateline@nbc.com  
[http://www.msnbc.com/news/dateline\\_front.asp](http://www.msnbc.com/news/dateline_front.asp)

20/20  
[http://www.abcnews.go.com/sections/primetime/2020/Primetime\\_email\\_form.html](http://www.abcnews.go.com/sections/primetime/2020/Primetime_email_form.html)

KAKE News-Larry Hattsburg/Hattsburg's People  
<http://www.kake.com/station/contact>

ABC News  
[http://abcnews.go.com/sections/2020/2020/2020friday\\_email\\_form.html](http://abcnews.go.com/sections/2020/2020/2020friday_email_form.html)

Nightline  
[http://abcnews.go.com/sections/nightline/Nightline/Nightline\\_email\\_form.html](http://abcnews.go.com/sections/nightline/Nightline/Nightline_email_form.html)

The Discovery Channel  
<http://extweb.discovery.com/viewerrelations>

The Oprah Winfrey Show  
[http://www.oprah.com/email/reach/email\\_showideas.jhtml](http://www.oprah.com/email/reach/email_showideas.jhtml)

The Montel Williams Show  
<http://www.montelshow.com/show/tell.htm>



OUCH Election Results  
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### OUCH Officers

President—Don Young  
Vice President—Steve Lichens  
Treasurer—Jane Phillips  
Recording Secretary—Melissa Fitz  
Correspondence Secretary—Michelle Adamson

### OUCH Board of Directors

Dave Edmond  
Marc Cox  
Elaine Holloman  
Linda Howell  
Riccardo Pentenaro

Congratulations to our newly elected officials. We extend an added note of thanks to the 2003 OUCH Officials and Board Members for all of their hard work, dedication and commitment to the organization.

### OUCH Advocacy Team

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The goals of the Advocacy Team are to:

- \* Provide education sessions for healthcare professionals
- \* Provide sufferers with information (video and print) that can be used to educate their local healthcare professionals
- \* Secure educational grant funding
- \* Establish association/affiliation with reputable and credible medical sources

The OUCH Advocacy Team is chaired by Cathy Lind. Randy Jones represents the PANJ Chapter and Tracey Wasinger is a general member. There is still a vacant position for a representative from CalOUCH and from the Florida OUCH chapter. Our goal is to have a representative from each chapter sit on the team. If you are interested in becoming involved in advocating for cluster headache sufferers, please contact Cat at [catlind@cox.net](mailto:catlind@cox.net) or the team at [OUCHadvocate@cox.net](mailto:OUCHadvocate@cox.net). Educating medical organizations and insurance companies is the key to providing consistent and effective treatment for this debilitating condition.

*When you're lying awake with a dismal headache,  
and repose is taboo'd by anxiety,  
I conceive you may use any language you choose  
to indulge in, without impropriety*  
— W. S. Gilbert

## The Cluster Quiz...

This quiz was designed to give you a quick, generic idea whether you may suffer from cluster headaches or not.

- #1) Do your headaches normally last LESS THAN 15 minutes?  
 Yes       No
- #2) Do your headaches normally last MORE THAN 4 hours?  
 Yes       No
- #3) Do your headaches normally switch sides from day to day or during a headache?  
 Yes       No
- #4) When you have a headache, do you normally seek a quiet, dark place?  
 Yes       No
- #5) When you have a headache, do you normally want to be around other people?  
 Yes       No
- #6) When you have a headache, can you normally lay down and be motionless?  
 Yes       No
- #7) When you have a headache, can you normally go to sleep to make it go away?  
 Yes       No
- #8) When you have a headache, do you normally experience nausea?  
 Yes       No
- #9) Are your headaches always on the same side of your head?  
 Yes       No
- #10) Do your headaches normally wake you up from a sound sleep?  
 Yes       No
- #11) Do your headaches normally occur at the same time of the year and same times each day?  
 Yes       No
- #12) Do you normally experience a stuffy nostril on the same side of the face as the pain?  
 Yes       No
- #13) Do you normally experience a "droopy" eyelid on the same side of the face as the pain?  
 Yes       No
- #14) Do you normally go from totally pain free to totally debilitated in 5-10 minutes?  
 Yes       No
- #15) Do you normally go from totally debilitated to totally pain free in 5-10 minutes?  
 Yes       No
- #16) When you have a headache, do you walk, pace, bash your head, thrash, scream?  
 Yes       No

### Evaluation

Questions 1-8 are not normally associated with cluster headaches. If you answered "Yes" to a few of these questions, you probably don't suffer from cluster headaches. *Please do your research and see a doctor!*

Questions 9-16 are normally associated with cluster headaches. If you answered "Yes" to most of these questions, you may suffer from cluster headaches. *Please do your research and see a doctor!*

### Follow-on

No matter what type of headache you have, the most important thing is that you see a health care professional for treatment. Self-diagnoses of head pain can be life threatening!

## LINKS...

Organization for Understanding Cluster Headaches (OUCH)  
<http://www.Clusterheadaches.org>

Cluster Headaches.com (CH.com)  
<http://www.Clusterheadaches.com>

United Kingdom OUCH site (OUCH UK)  
<http://www.Clusterheadaches.org.UK>

German OUCH site (OUCH VCH)  
<http://www.Clusterheads.de>

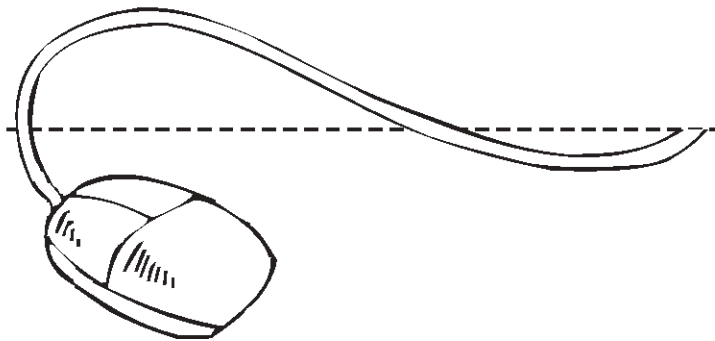
South American Cluster Headache Site (Cefalea en Cluster)  
<http://www.Civilizacionweb.com>

Italian OUCH site  
<http://www.OUCHitalia.it>

Clusterhoofdpijn-Dutch Cluster site  
<http://clubs.nl/community/default.asp?club=clusterhoofdpijn>

Headache Support Groups  
<http://Headachesupportgroups.com>

The New England Center for Headaches  
<http://www.HeadachesNECH.com>



### Jason Aubin

*...continued from page 3*

gan applying meditative and calming exercises I learned to control my body even as the worst pain washes over me and my muscles scream - DO SOMETHING!"

When interviewed, Jason was asked what was his greatest fear of going to Iraq. "My parent's receiving a flag." He added, "I do not fear the pain or the thought of death, just the thought of my family grieving". I am sure we all wish Jason a safe return.

Jason will deploy to Iraq sometime in February of 2004. He has expressed a desire to remain in contact with his fellow "Clusterheads". As an added bonus, Jason will be writing stories for the newsletter "from the field"- A wartime correspondent for the newsletter. Look for information from Jason in the March 2004 issue of the **OUCH Newsletter**.

## OUCH FUNDRAISING

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Tina Brown won the auction for the angel with her bid of \$30.00. Tina said she was thrilled with the angel and that "the money I paid is WELL worth it - especially since it's going to OUCH." Jean French won the auction for the lighter with her bid of \$150.00. Jean also stated that the lighter is beautiful and "No amount of money is too much to support this great site."

Many other items were auctioned off, such as drawings and paintings done by clusterers. Also a beautiful bunny, and photographs items donated. A few of the many that have been donated and have been or are being auctioned off at this time.

*"No amount of money is too much to support this great site."*

headache sufferer. These are just a wonderful items

There are also plans for an online Yard Sale and a Bazaar. The Yard Sale will consist of donated "white elephant" items. These items will be sold on line with the profits going to OUCH (minus shipping). The Bazaar will primarily be craft items, and other "odds and ends". Be sure to check the message boards at [www.clusterheadaches.com](http://www.clusterheadaches.com) and [www.clusterheadaches.org](http://www.clusterheadaches.org) (OUCH) for future announcements concerning fundraising events.

Special recognition and a big thank you is due to the many talented people that have donated their time and talents to this great cause and to those of you who have purchased these items.

## OUCH NATIONAL CONVENTION 2004

By Donna Delacerda

After months of deliberation the site has been chosen for the 2004 OUCH National Convention. Nashville, Tennessee is the place to be for cluster headache sufferers and supporters July 16-18, 2004. This year's convention committee is co-chaired by Leesa Dobson and Jayne Salter.

The convention will be held at the Holiday Inn Nash-Vanderbilt. This location was carefully selected based on its amenities, handicap facilities and close proximity to emergency medical care.

Registration costs are \$75.00 per person and include: Technical sessions, the banquet on Saturday night, a convention T-shirt and other gift items. Registration can be done online at <http://www.clusterheadaches.org/conventions/2004/index.htm>. Payment can be accepted by Pay Pal or those wishing to pay by check can download and print the mail in registration form.

## The O.U.C.H. Store On-Line

<http://clusterheadaches.org/store.htm>

HELP SUPPORT OUCH. BE STYLISH.



Lodging is not included in the reservation costs however; reservations can be made by calling 1-800-633-4427. Be sure to advise the reservation clerk you are a member of OUCH.

The agenda is as follows:

Friday, July 16th .....	Meet and Greet
Saturday, July 17th .....	Technical Sessions
	Banquet Dinner
Sunday, July 18th .....	Free Time

Many events are still in the planning stages. Additional information will be published as it becomes available. For questions please contact the committee chairpersons or visit us on the web.

## COPING WITH CLUSTERS: Musical Clusterheads

By Patricia Colón

The mechanisms people use for coping with cluster headaches can vary as widely as personalities do from one person to the next. We all know how wonderful music can be in our lives, how deeply it can move us, the inspiration it can invoke, and the comfort it can bring. Music can soothe a crying infant, change the tone of a movie, or create a romantic mood for a proposal. Teenagers, playing their brand of music, can even their drive parents to cut off the electricity privileges for a week! Amazingly, there is a song for every emotion, up or down, a style for every feeling, and whether it's new age, country, blues, funk, heavy metal, classical, or rock, it can accompany us in the good times and the bad. Along this vein, I posed questions to cluster headache sufferers about their connection to music:

**"How do you relate music to cluster headaches, if at all? Is it a coping mechanism for you? If you are a musician, what does it mean to you?"**

**Thomas Mikel** (thomas) – "When I'm getting hit, I cannot take any noise except listening to Disc 2 of the Fleetwood Mac box set. It just seems to relax me and make the CH (cluster headache) a little more bearable. I always play it after taking my abortive and waiting for it to work. It's just like the old saying 'music soothes the savage beast' it helps me to deal with the pain just a little bit better."

**Jimi Hendrix** (Jimi) (and yes that is his real name) – "Years and years ago when I was having them and didn't know what they were and was taking nothing for them. I used to put on an album when I was home

and felt one coming on. It was the Door's Greatest Hits. By the time the front side was finished, it was usually gone. (I have) no clue why I chose that one. I love music, like to sing etc. but cannot find any correlation betwixt the two now."

**Svenn Thorn** (Svenn) – "Can't live without the music. My 'brain washer' gave me this idea to try under an attack: Try put on your favorite CD on LOW volume and try focus on listening to the music during battle with the 'beast' just to try take the focus away from the pain. That advice has helped me more then one time for sure. We have to do whatever it takes to take the focus away."

**Deanna Sharp** (Simplevox) - "I sing in a band, but usually have to take a break from it when I am 'in season'. I absolutely love to perform, but the older I get, and the more CHs I get, the more that part of my life seems to get put on the back burner. Score one for the beast! I have never gotten a CH while I was singing... have had some during practice. I honestly have never tried to mix music with a CH. I might try it next time! You can listen to my band's music at [www.simpleband.com](http://www.simpleband.com)."

**Stephen Correa** (EyesAfire) - "When having a CH, I don't think about music at all. It is the farthest thing from my mind. I think that music has strong associative properties. Music can serve as a 'marker' in one's life... different life events can be remembered through music. I would not want to think of music during a CH for fear of spoiling my appreciation for that type of music through process of association."

**Paigelle** – "I listen to music constantly. I always put a CD on that I love when I am in pain. Something about that helps to drown out other things. Use to always date guitar players also, but that is another story. I think it is the noise factor

when playing the guitar. Of course a guitar player I dated gave me headaches."

**Pam Jones for Brad Jones** (cootie/ Brad) - "Brad cannot stand any noise or light or anything when being hit. He doesn't listen to any music at that time what so ever. He loves music though. He plays harmonica with a few friends' bands when he can, especially at the summer parties and bashes we go to."

**Carl Daniels** (CarlD) – "I love all kinds of music, even some classical, new age, jazz/fusion, and classic rock, but it seems that once I started getting CH, my own music began to get very dark. I have written things many will never see. I take all of my anger, rage, violence, and destruction not on people, not on the establishment. I take it out with a pen and paper. I take it out on my screams. I take it out in my music and performance. Many are shocked when they hear the mellow stuff I have done in contrast."

**Ramon Brown** (Cerberus) - "My music has been there for me at every point of my CH. Sometimes in defiance of the ensuing attack I'll cue up the most brutal, punishing heavy metal I can find and blast it at the highest volume attainable. Other times, I use it to soothe me into relaxation after an attack right when my meds (medications) are kicking in. Its always there when I'm mentally worn from battle, or when I'm fresh into cycle its there when I need it. Of course, nothing being typical with CH neither is my musical taste; there are times when all I want to hear is silence. And there are times when I sit outside at night in summer and listen to the symphony of crickets and cicadas droning out their memories of daylight. Sometimes my music speaks FOR me...if there is a friend in need or in pain I can send 'em a song to cheer them or cue one up in memory of friendships passed away. It can heal the deepest wounds and open

the most bittersweet of memories. Music focuses my subconscious and conscious selves into one being more complete with music than without. I'm never without it."

**Traci Combs** (Tiannia) - "When I am getting hit, I want my music. This is always how I have dealt with pain even as a small child. On the way to the hospital, I would be singing in the back of the car. More then once my mom thought I was lying about being sick cause she would hear me singing. Music, especially songs that I know and love allow me to focus. This helps me with work and my kids. It is what lets me still function while the beast in tearing through my head."

**Mike Mitchem** (Mikey) - "I've experimented with listening and playing my guitars. I seem to get the best results sometimes when I get out one of my electric models, and plug up with headphones attached. I up the volume a pretty good amount, and I think I do that because of the pain, and to let out the frustrations of the pain and suffering I'm going through. Sometimes I use an acoustic model and try to mellow out, or I'll do the same with one of my favorite CD's. The most effective I've seen so far, has been the electric guitar thing. Just jammin' really hard and fast, trying to work up a sweat with the volume up really loud. It's hard to explain, but sometimes you just need the opposite thing that you would feel that wouldn't work, that may just do the job for you at the time."

**Mike Kenney** (Miklos) – "Music, per se, does not help during a cluster headache. I am pacing so badly that I could never hold onto an instrument much less play. Listening to music does not help either since I really prefer silence and darkness during a headache (With lots of ice and as few clothes as the law allows.) Since my episodes usually onset in January the former items are likely to be available."

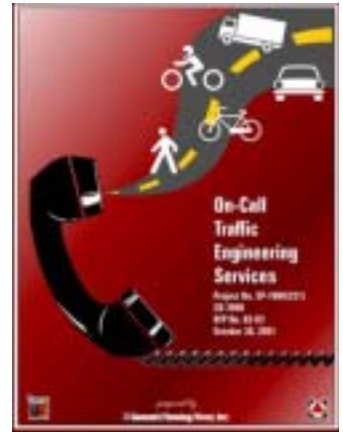
# CLUSTER ART

**Paul-Baptiste Baca** (Hirvimaki)

is a Clusterhead and graphic designer and artist. He lives and works in New Mexico. He holds the ostentatious title of Senior Graphic Designer in marketing and business development at Gannett Fleming, an Engineering/Consulting firm.

When he is not working — yes this does happen occasionally — he spends his time with his wife and

their three dogs driving their red Jeep Wrangler over large rocks in New Mexico, Colorado or Utah or working on the various art projects that clutter his studio at home. Scattered about on this page are some samples of the various types of work he does, which include graphic illustration, graphic design, airbrush, water colour and pen and ink.



Hirvimäki

# Smiles-Across-the-Miles

## O.U.C.H. — A Historical (and Sometimes Hysterical) Perspective

by Barbara D. Henderson

Clusterheadaches.com (CH.com) has been a lifeline for so many cluster headache sufferers since April of 1998. OUCH evolved from here. The history of OUCH is the people. Those people who, although suffering the most debilitating pain imaginable still could laugh at themselves while they shared experiences with other sufferers. These articles are about those people of Clusterville (CH.com).

Bob Kipple is one of the Old Timers in Clusterville. Came here in 1998. Brought his wife, Judy, and a bad headache. Bob did a lot for Clusterville. He gave support to a lot of people. We were having trouble describing our pain, so the son of a gun just sat down one night and wrote us a pain scale. Now it's known as the **Kip Scale** and is used worldwide to describe the pain of Cluster Headaches. When we thought of forming an organization, he was right in the middle of that too. He and Judy flew to Rochester NY to meet in a guy's garage to help put together OUCH and he was our VP for a couple of years.

But the one thing Bob will never live down was his night walk and the Rotweiler: From the archives:

When will it end?

Posted by Bob Kipple on April 13, 1999 at 18:48:20

My primary way of dealing with a full blown 8 to 10 CH is walking (pacing?). When we moved to this very rural location in '80, the walks around the dirt roads seemed a little more soothing than pacing

around the pool at our former house. The only problem in this rural paradise was dogs. After standing off 3 pit bulls, 2 Dobermans and a variety of yuppies, I started carrying a gun although the intense light of my dive light would usually stop them. The closest I came to using it was on a very dark night I was rounding the corner on the road to home when something "bumped" me. I turned on my flashlight and there was a HUGE Rotweiler pacing with me. Out comes the gun!!! But Mr. R wants to be my friend, i.e., takes my hand gently in his mouth (dog spit, ugh). OK sez I, dog wants to be my pal (stupid dog really wanted to be my lover). We go around the corner and Mr. R runs in front of me, trips me and now I'm on hands and knees. Next thing I know, there's a paw on both shoulder and a rhythmic bumping on my butt. AAARRGHHH. Grabbed Mr. R by neck while getting gun and getting ready to defend my honor. Mr. R just kinda whimpered, like 'Did I do something wrong?'. OK sez I, you're spared. So I finally get home, the beast has been walked off, and I tell my wife of my ordeal... First, she offers to call the rape crisis line and then worries about what to name the puppies!!! I really love this lady, she can sense when I can appreciate this humor. Painfree and remission for all. Watch out for large dogs, we suffer enough.

*\*\*At last check, all puppies are fine and living on an undisclosed island in the Caribbean, where Kip visits them regularly. And no they're still not up for adoption.*



Christopher Smith

## OUR NEW BUDDY

by Grant Samborn

Recently, we had a new, special addition to our family. Christopher Smith was declared an official "Clusterbuddy" on December 4, 2003. We were first introduced to Christopher in early September of this year by his Aunt Nancy (OneEyeBlind). Since that time, we have all grown to love and care about him through her regular updates regarding his progress.

This extraordinary young man has been an inspiration to us all. His positive attitude and outlook on life despite his illness has touched our hearts and our minds.

At the age of 6, Christopher he was found to have a Ewing's tumor that resulted in the loss of one leg. Recently, he was diagnosed with a brain tumor. He is currently preparing for a stem-cell replacement operation at the Hershey Medical Center in Hershey, PA and will remain there for two to three months.

The first "harvest" for the stem cells took place on Wednesday (12/10/03). He is hooked up to a machine with a catheter placed in the jugular vein of his neck. The machine pumps the blood out, harvesting the stem cells (which are newly formed cells that have not yet attached to any part of the body) and then the blood is re-pumped back in to him. The stem cells will then be saved to re-inject into his body after massive chemo treatments have been done to kill any cancerous cells he may have. The new stem cells, once injected back are able to attach to any organ needing them, and grow non-cancerous new cells. It's all quite amazing how far medical technology has come.

...continued on page 11

## CLUSTERHEADS SEEK-N-FIND

C	H	A	R	L	I	E	X	I	B	B	O	B	J	B	V	T	N
A	L	U	S	E	V	R	E	K	A	I	E	I	K	I	M	U	N
R	P	U	B	G	I	R	L	A	R	L	N	S	T	G	I	R	A
L	O	E	S	I	G	R	A	M	B	L	Y	U	R	D	K	T	A
D	R	L	P	T	I	M	I	A	Y	A	P	J	A	E	S	R	
C	O	I	R	H	E	O	N	V	R	J	J	O	N	N	Y	E	A
K	X	N	E	O	S	R	E	R	A	N	U	X	T	K	D	E	T
R	Y	O	N	M	U	E	C	I	D	A	V	E	R	T	A	B	R
A	C	W	S	A	E	E	A	H	F	N	Y	I	R	O	L	E	K
M	O	M	E	S	D	M	T	S	U	R	K	I	P	T	S	E	Y
W	O	O	B	I	E	T	L	E	B	C	W	P	O	K	S	G	P
O	T	T	O	N	N	I	R	A	C	K	E	N	N	A	E	P	
Y	I	S	B	R	A	I	N	C	R	A	M	P	S	I	B	V	A
P	E	P	P	E	R	M	D	O	N	I	M	I	J	V	X	E	H
S	S	E	N	O	I	L	I	T	T	L	E	D	E	B	T	T	R
N	A	N	C	Y	C	R	V	L	F	F	I	T	S	A	M	S	M
A	S	O	L	K	I	M	M	E	R	I	F	A	S	E	Y	E	Y

**THERE ARE 58 CLUSTERHEADS HERE  
CAN YOU FIND ALL THE NAMES?**

## The O.U.C.H. Classified Ads

Merry Christmas to Clusterbud, Christopher Smith, and the rest of my Clusterville family! Thanks to all of you for being there!  
— Chuck Setzco  
(ClusterChuck)

Happy Holidays from Your Prez!  
— Don Young

A Christmas Wish. May the Happiness of Christmas, Be in the hearts of each clusterhead and supporter to stay, And to brighten all y'all's moments, Long after Christmas day! Merry Christmas from HSG.  
— Elaine and Michelle

As the King of CH.COM I here by declare September 4th PF day, if you are not PF on this day you will be locked up and killed...  
— King jonny

Merry Christmas and Happy New Year to all my fellow clusterheads. May God bless each of you with love, prosperity and good health this holiday season.  
— Little Deb

Merry Christmas and Season's Greetings to all of my Clusterhead and Supporter Friends. May this joyous season find you full of peace and happiness and free from pain.  
— Donna D.

Hyvää Joulua! Merry Christmas! Warm greetings to everone in Clusterville. May the blessings of the Season bring you joy, laughter and love.  
— Paul-Baptiste & Eveliina

SHOP at these retail stores and help support OUCH

<http://www.clusterheadaches.org/cgi-bin/ouchmall/SuperLinks.cgi>



## Another Kind of Pain

by Jackie Warrior

Posted on the message boards at <http://Clusterheadaches.com> on September 17th, 2003 at 3:02pm

I'd like to start by telling you all what this post IS NOT. This is not a post or story that is meant to be self-serving. It's not a post about who suffers more or whose pain is the more hurtful. It's not a "complain" post or a "whine" post.

It's a post about what it feels like to be me...the wife of a chronic clusterhead who I love with all my heart. It's a post about what it feels like to be me when I read so many of the sufferers posts because I have seen with my own eyes the pain they are talking about.

Clusters hurt supporters hearts...

I've watched Blake reeling in pain for endless hours. I've heard him beg God to kill him. When God doesn't he's begged me. That's heart pain.

I've seen Blake (some mornings looking like he just walked out of a concentration camp) eyes sunken in, no color, and no facial expression. I ask him if he'd like a cup of coffee and

say 'you better hurry up, honey, or you'll be late for work'. What I'm thinking is how can this man make it another day...how can he go to work. But...I know I have to make him try. I know I can't let him give up. That's heart pain.

At different times I've asked the doctors to change Blake's drugs.

I've done this more than once and it's usually when he's in "high cycle". My theory is we have to keep

trying...we have to keep looking.

One time when we changed drugs it made it much worse.

Right in the middle of a Kip10 he's begging me to please never try another drug...please never ask him to do this again. That's heart pain.

I've intentionally made Blake mad when I feel he's about to give up.

I've pissed him off just to get his blood flowing and get the heart rate up. It works but it just about

does me in when all I really want to do is hold him and cry. That's heart pain.

Clusters hurt supporters egos...

I'm a bit of a control freak. I like to take charge and fix things up. I like to make things better for friends, family and loved ones.

But you know what...there's not a damn thing I can do to stop the pain when the demon hits. I can't threaten

him, scare him away, bust his balls or buy him off. I have to accept that I can't make it all OK for Blake until the demon let's me. I have to stand by in a helpless state. That's ego pain.

There's one more pain and it's called guilt...Blake and I are husband and wife. We are soul mates.

We are best friends. We are supposed to share everything...the good things and the bad...the tears and the laughter...the pain and the

"feel good" times. I have begged God to put the demon on me...to give Blake a break...to leave him alone for just one week. But...it never happens. Blake has to endure all the hits and that's not right. That's guilt pain.

Love to you all...sufferers and supporters alike

Jackie

LOL...one more thing. My theory is never let 'em see ya cry, never let 'em see ya sweat, never let them see any doubt on your face...hang tough and they'll hang tough with ya...fight the demon with them and they won't give up...tell them that tomorrow will be better and they'll try it another day.

*[Editors Note: I wanted to interview a supporter for this issue of the newsletter. After reading this post, I do not feel that I could have written anything that could better describe what life is truly like for a supporter of a cluster headache sufferer. Thank you Jackie for such a soulful insight.]*

***I have to accept that I can't make it all OK for Blake until the demon let's me.***

## OUR NEW BUDDY

...continued from page 9

The first harvest, due to Chris's low blood counts, only harvested 10% of what is needed for a successful re-implant. Chris will be staying, and three additional attempts to "harvest" the necessary amount of stem cells will be done in the coming week. If the doctors are still unsuccessful, they will send him home, waiting for the blood counts to go back up and re-attempt the harvest after Christmas.

Let's please all remember Christopher and his family during these difficult times. Anyone wishing to donate gifts can find a list below. Cards and Letters are sure to be met with smiles. Be sure to write "Clusterbuddy" somewhere on the envelope or card so that Christopher will know that it is from his new family.

His address is:

1003 Dellville Road  
Duncannon, PA 17020

Christopher likes:

- Anything to do with his computer including graphics programs and magazines
- Unique lighters for his lighter collection (can be found cheap at flea markets etc.)
- Little electronic gadgets
- Cool t-shirts with small logos (Christian, computer etc.) Orange and blue.
- Hot sauce
- Beef jerky
- Red licorice nibs
- DARK chocolate
- Slushie packets

Christopher's younger sister Katie (14) likes:

- Cool Lip Gloss
- Starburst, Skittles and Beef Jerky
- Audio story tapes
- Things for her room (blue)
- Picture Frames
- Small silver earrings and necklaces
- Drawing and Art supplies
- Contemporary Christian music

O.U.C.H.<sup>TM</sup> Organization for Understanding Cluster Headaches

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MAIL TO:

MEMBERSHIP  
APPLICATION

# O.U.C.H.

Organization for Understanding Cluster Headaches

Complete this application and mail it to:

O.U.C.H.

807 E. Braodway  
Gladewater, Texas 75647

FIRST NAME: \_\_\_\_\_ MI: \_\_\_\_\_

LAST NAME: \_\_\_\_\_

ADDRESS: \_\_\_\_\_

ADDRESS (2): \_\_\_\_\_

CITY: \_\_\_\_\_ STATE: \_\_\_\_\_ ZIP CODE: \_\_\_\_\_

PHONE (DAY): ( ) \_\_\_\_\_ PHONE (NIGHT): ( ) \_\_\_\_\_

E-MAIL: \_\_\_\_\_

HAVE YOU EVER HAD CLUSTER HEADACHES?:  Yes  No