

## FROM THE EDITOR

Ted Marcus

**Welcome** to the first edition of the Organization for Understanding Cluster Headaches' (O.U.C.H.) newsletter. You are now witnessing our public embarkment of a painfree journey into the land of cluster headaches.

It's been said that if you can't dazzle them with brilliance then baffle them with bologna, (or words to that effect). This newsletter will help you with the prior.

When a post was sent to the CH.com message board ([www.clusterheadaches.com](http://www.clusterheadaches.com)) suggesting the formation of an organization that would deal with issues pertaining to cluster headache (CH) sufferers, few people, if any, probably had an idea how far that idea would go. However, yesterday's dream is today's reality. There is now a non-profit organization devoted to CHs. And this fledgling organization

is growing everyday. We can all help it grow faster and larger by sending in the appropriate membership fee along with the membership application that you'll find at the back of this newsletter.

This newsletter, a product of the Education Committee, is but a part of O.U.C.H.'s work. The mission of the newsletter is to be informative to both the medical community and also to people without a medical background. How will we do this? Well, if you're left-brain itchy and have an interest in the more technical aspects of CHs, you'll find that information here. If your itch originates from the right side of your brain and you want to see or read CH-related artwork, you'll also find that here. Or, if you are a sufferer and have never met another, hopefully the personal accounts you'll find in these pages will help you to realize that you were right all along, despite what you may have heard from those who don't

understand the condition. These headaches, sometimes referred to as "suicide headaches" due to their severe intensity, ARE as bad as you thought. They ARE more torturous than the everyday sort. They DO bash your head in with more strength than a migraine. You ARE NOT weaker than your bosses or co-workers who castigate you and have given you the "I've-functioned-fine-at-work-with-a-migraine-and-expect-you-to-do-the-same-with-whatever-it-is-you-have" speech or look. Here, you'll find that many of your personal battles – physical, mental, professional and social - have been justified. And hopefully, we will better prepare you for the next ones.

I now invite you to travel through these pages and journey with us...

*Ted Marcus  
Education Committee Chairman*

## What is O.U.C.H.?

*O.U.C.H. has become a reality...*

Born through the internet, the international, not-for-profit Organization for Understanding Clusterheadaches (O.U.C.H.) started when a group of people around the world who suffer from the syndrome known as cluster headaches met at the website CH.com ([www.clusterheadaches.com](http://www.clusterheadaches.com)).

CH.com was created by Daren "DJ" Johnson who suffers from this rare syndrome in the hopes of finding other people who suffer from cluster headaches. He succeeded.

To date, thousands of people have found and visited CH.com. They are able to communicate with each other through an online message board. A gentleman by the name of Bob Havers ("Ic Bob") created the idea of O.U.C.H. with a humorous post to the message board. Then Barbara D. Henderson took the idea and made it a reality by creating a legal not-for-profit charter. With the assistance of DJ and several Officers and a Board of Directors; O.U.C.H. is a reality.

This international organization serves people with cluster headaches, their families and others affected by the affliction. O.U.C.H. intends to educate and spread understanding and awareness about Cluster Headaches. O.U.C.H. will hold a convention every year to reveal the latest Cluster Headache research and to nominate Officers and Board of Directors to the organization. Its first annual convention will be in Las Vegas on August 4-6 in the year 2000.

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**What is a Cluster Headache?**

Ted Marcus

*.....the most excruciating pain...  
 ..... that there is to endure...*

It wasn't supposed to be a day, which later would stand out as a day to remember. I was supposed to get up, go to work, come home, maybe read or watch some television and go to sleep. But it didn't turn out that way at all. Instead I woke up to the beating of a lifetime. I woke up with the knowledge that some unholy monster had sent his minions inside of my head to claw their way out of my left eye with their sharp, acid-covered talons. And while they would dig out, he would give them a hand by standing in front of me and drilling his venomed fang inside of that eye, apparently to save them some work or add to my torture. The venom spread throughout the left side of my face and attacked my temple and upper gums. In past bouts, I've tried lying back down, only to discover that this gives the hellish creatures more strength, so I remained sitting. It was far past the point where I could move much without exacerbating the problem. Instead, I just sat there wiggling my toes and fingers to achieve what many others achieve by pacing. Needless to say, I couldn't make it to my phone to call work and let them know that I would be late and if I could make it to the phone, I surely couldn't verbalize any recognizable words. I could just mumble.

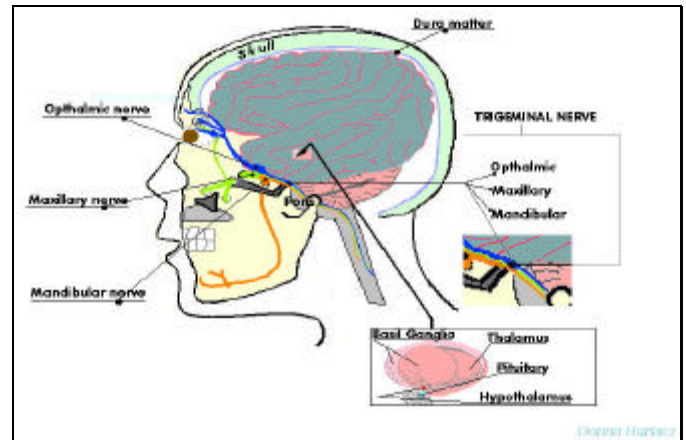
Well, the creatures made their way out of my eye and I was already 15 minutes late for work. I called my boss to tell her what had happened and that I was heading in. By the time I arrived to work I was 1/2 an hour late. The boss pulled me aside and gave me a 15 minute dressing down about being late and that she's come to work and had to do so while suffering headaches. I tried to explain to her the difference between everyday type of headaches and cluster headaches. She tried to explain to me the difference between employed and unemployed. The education that she was giving must have gotten through to me better than the education that I tried giving to her because at the end of our conversation she managed to give me unemployment, while I had no luck in giving her a cluster headache, let alone an understanding of it.

**So, just what is a Cluster Headache?**

(Refer to glossary for words with asterisks\*)

So just what is a cluster headache? It's an affliction that, with current figures, tortures 0.1 percent of the population with males being afflicted on a higher percentage than females (which by no stretch of the imagination means that women don't also suffer from them). For many sufferers an attack begins and reaches its peak within 2-15 minutes.

Often it is brought on within 2 hours of going to sleep and while in the REM phase of the slumber. It has been described as the most excruciating pain that there is to endure, including childbirth and amputation. An attack can last from 15 minutes, (on the low side) to 4 hours, (on the high side). It generally becomes most painful in the **periorbital\*** region and also attacks the **temporal\*** region and around the gums. It is widely believed that these areas are most affected because of an irritation to the **Trigeminal nerve\***. Besides its most debilitating symptom, the pain, there are a host of other symptoms: change in eye and pupil size, congestion and/or runny nose, drooping eye, a feeling of overheating and breaking out in a sweat.



Other than sweating and sometimes the congestion, all the symptoms will only occur on the side of the pain which most of the time is on the same side each attack. Although, attacks can occur on the opposite side too.

For 80 percent of sufferers, the cluster period is episodic, which is to say that they go into remission more than 2 weeks at a time within a year. They often get attacks at the same time of year, (Spring and Fall). This may be understood more by a discovery of Dr Peter Goadsby, Professor of Clinical Neurology at University College, London, who found that CH sufferers have a subtle increase in the size of the posterior section of the **Hypothalamus\***, which, along with other functions, regulates our **circadian rhythms\***.

Chronic sufferers, (20 percent of the CH population) are those who have no more than a 2 week period of remission within the span of a year.



Organization for Understanding Cluster Headaches

**Membership in O.U.C.H.**  
*We need YOU*

We need you to join our Organization. The Organization for Understanding Cluster Headaches has just begun its first membership drive. If you have cluster headaches, have a spouse or loved one with cluster headaches, a friend with cluster headaches or are a concerned medical professional with an interest in cluster headaches **WE NEED YOU**. How do you join and what are the benefits of membership? Well, joining is real simple. You need to fill out the form on the last page of this newsletter and mail it, along with a check (personal is fine) for \$25 (U.S. Funds) to O.U.C.H., at 807 E. Broadway, Gladewater TX 75647. Join O.U.C.H. and you will promptly receive voting privileges, you will receive information about our annual convention and you will be apprised of all the latest developments in cluster research and treatment. Most important of all you will become a member of a non-profit organization so your membership contribution is fully tax deductible. Our final word about membership: We have asked you for some personal information in the membership application. We pledge to keep this confidential and **WILL NEVER** provide any other group or commercial organization with this information. So you will not be bombarded with solicitations as a result of your membership in O.U.C.H.

**PROFILE:**



**Daren "DJ" Johnson**

by Linda Davis (DJ's Mom)

**DJ Johnson**

Born in Goldsboro, North Carolina on October 25, 1966 at 1:20 pm Daren Matthew Johnson, DJ, weighed 7lbs, 15 & 1/4oz. I guess those statistics stay with a mother!

DJ was born the first year his dad was in the Air Force and was seven when his father and I divorced. The summer before his

13th birthday, DJ went to live with his Dad. It was a difficult adjustment for "Mom", but a heart felt and expected desire for a teenage son to want to spend that part of his formative years with his father. His Dad was out of the military by then. He and DJ's stepmom, Robyn (one of the best and sweetest Christian women I have ever known) made Edwardsville, Illinois their home. I became "Aunt Linda" to their children Garrett and Jordan. It was ultimately a good arrangement for all concerned giving DJ and I a head start on the inevitable "letting go" process that comes to all parents with their children.

DJ was 18 and in the Air Force when he started having "headaches". The only other medical problem that I knew he was concerned about during enlistment early in 1988 was a functional heart murmur acquired at birth, and one proving to be no health consequence in his adult years.

Most of what I know about Cluster Headaches and how DJ has suffered with them is sketchy at best. I think of him having a high pain tolerance, because over the years he has never been one to complain much about the pain or inconvenience of them to me even though they have been the source of considerable upset in his life.

The first time I became aware of problems with headaches, DJ was married and stationed in Turkey at Incirlik AFB. That was several years into his military career, the first two years being spent in Seattle at McChord AFB. While DJ was stationed in Seattle he was misdiagnosed as having migraines. Doctors treated DJ as a migraine patient for two years.

As DJ was about to begin a tour in London, at Lakenheath AB, a doctor at the Army medical center at Ft. Lewis, Washington diagnosed him as having Cluster Headaches.

During DJ's tour at Lakenheath, he had three cycles of cluster headaches. DJ saw several Neurologists there and tried many medicines before finally being diagnosed as an episodic sufferer. From England, DJ's next tour took him to Incirlik AFB in Turkey.

It was in Turkey where DJ met a doctor that had some practical knowledge about cluster headaches and was the first to begin experimenting with methods to treat him. This was the first doctor that gave DJ abortive treatments, using oxygen as opposed to a shot of Demerol.

I think until then, all they knew to do when the pain became unbearable was take him to the hospital and give him a shot of Demerol that would make him go totally to sleep. When it was discovered pure oxygen would help, he was issued an oxygen tank. He still keeps one at home today. Unfortunately, cluster headaches still awaken him from a dead sleep.

Continued....

**DJ JOHNSON, continues.....**

Twice so far during his military career, DJ has been tested for Cluster Headaches at the Air Force medical center in San Antonio. The most recent being approximately a year and a half ago. At that time there was genuine concern that he would be forced to retire as a result of them. I do not know many details about those months of stress and turmoil, other than that his career of 10+ years and what livelihood he enjoys as a result of that was in jeopardy. During that period of time, he received enormous and gratifying support from people all over the world through "clusterheadaches.com". I remember DJ telling me about one fellow sufferer and gentleman of "position" in London, who was ready to come to the States to testify on DJ's behalf, if he would only say the word! Ultimately, the Air Force once again settled that issue in his favor. I believe he was told that if he so desired to take it, cluster headaches were reason enough to be awarded an honorable discharge. Otherwise, his military record was exemplary, and they would continue to work with him regarding pain management.

When DJ returned to the States for his most recent tour, (here in Kansas) he was given injectable Imitrex as an abortive treatment for his Cluster attacks.

It is a combination of these shots he administers to himself and oxygen which consistently provide the greatest relief from the "headaches". DJ has done interviews for "clusterheadaches.com" on several different occasions. Once in his home with a local TV news program last year. I am also aware of requests from the medical community wanting to know if he would write articles for their publications. He is quick to tell them he has no credentials in the medical field, only practical knowledge acquired in his pursuit of helpful information as a fellow sufferer.

Elaine Holloman [pictured with DJ] was the first person that DJ personally met on a one-to-one basis who has Cluster Headaches. Last year she and her daughter drove from New York State to Wichita, Kansas before making their way back to Georgia, where they live. She was also the first person, beside himself, whom he witnessed experiencing an attack. This last September he and Elaine traveled to New York and spent a week with Amanda Best, another



CH.com friend at her apartment in Manhattan as she was struggling to recover from complications developed from extended treatment of cluster headaches.

As for DJ's computer expertise, his skill and knowledge are self-taught. It was during his tenure at Incirlik AFB that he bought his first computer. DJ has always enjoyed learning and is a quick study of practically anything else he chooses to pursue. I remember several years back when he bought a Sony movie camera. At the time, it was the latest in one-candle lux power and state of the art technology. Literally, in a matter of hours, DJ knew how to make that camera do most anything the manual demonstrated.

In conclusion; how would I describe my son? He is the ultimate "gift of life" to this Mom. He is a treasure!



**NEWSLETTER STAFF:**

Editor.....Ted Marcus  
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We need your feedback and welcome any ideas of what you'd like to see in future issues of the Newsletter. Please direct all correspondence about the Newsletter and/or the Education Committee to:  
[ClusterTed@hotmail.com](mailto:ClusterTed@hotmail.com)

**GLOSSARY OF TERMS**

**Circadian Rhythms** -- Physiological events that occur in our bodies through a roughly 24-hour biological clock. One way we witness this is when our bodies let us know each night that it's time to go to sleep.

**Hypothalamus** -- The endocrine gland in the brain that regulates hormonal secretions and controls circadian rhythms.

**Periorbital** -- Area surrounding the eye socket.

**Temporal (Region)** -- The area surrounding and including the temples.

**Trigeminal Nerve** -- A large mixed nerve connected to the brain stem by its two roots: A large sensory root and a smaller motor root. From the sensory root (the section through which the pain impulses travel through) it splits off into three branches. One branch (the ophthalmic) passes through the nose, sinus and eye. Another branch (the maxillary) passes through the upper mouth region, including the upper lip and gum. And the third branch (the mandibular) passes through the tongue, lower mouth region and jaw.



# Cluster Art

(ed. note: This art page will be an ongoing feature of the newsletter. While technical explanations of cluster headaches (CH) are important for the understanding of the condition, so too, we believe, is the artistic expression for a more complete understanding. If you'd like to see your work in print and are a CH sufferer, supporter, or even just know someone with CHs and can't make heads or tails out of the situation (in other words, if you're touched in any manner by the condition) you may submit your original poetry, prose, visual art of any sort to: [clusterted@hotmail.com](mailto:clusterted@hotmail.com). On the subject line write "Cluster Headache Artwork." There is no deadline at present. There is no minimum requirement for submissions. Sometimes the page will have the works of just one person and other times it will have several people included.)



**Angela Gilbert** (1969-2000), a chronic cluster headache sufferer, has chronicled the torture cluster headache sufferers endure. Following is some of her work from age 12-30. Much of it deals with the physical pain, but she also depicts the suffering of feeling alone when even our loved ones are not understanding or accepting of this condition. She also writes of the elation felt after a given amount of painfree time.

### Rainfall

(age 12)  
Rain keeps pattering.  
Washing the lane  
it glistens and christens  
the world of pain.  
Drops down-splattering  
the song of rain.  
Shh... my head listens.

### Burning Inside

(age 13)  
It's only a fire  
burning inside.  
Tearing my head  
open and wide.  
It's an occurrence  
that keeps me awake.  
A disguise for this pain  
I try to make.

### December Pain

(age 15)  
As the glints of light  
filter the fading light,  
I wake and remember  
the pain of December.  
It's gone today  
(the hurt swept away).  
As I face the morning's glow,  
the sounding crow,  
I think and smile  
to myself a while.  
Because I can face the day  
and love it anyway.

### Chasm of Pain

(age unknown)  
Wave after wave  
it crashes  
into the chasm of my existence.  
Pulling me under  
and into its void.  
No sound. No reason.  
No hope to escape  
its pain.  
I surrender  
unable to fight.  
Destroyed and devoured.  
Swallowed whole  
and spit out again.  
And forced to fight  
one more round.

### It's

(age 16)  
It's razor sharp,  
the pain.  
It's sliver thin,  
the game.  
It's hours late  
the hope.  
It's concrete hard  
to cope.

### In Dreams

(age 30)  
In dreams  
I feel the threads of pain.  
They stitch into my realm again.  
Pain laughs  
and whispers  
"It's time to wake."  
"NO!" I scream.  
"Not tonight."  
Let me dream."  
It laughs and calls me by name.  
"Come on my dear."  
Let's play the game."

### All Mine

(age 18)  
Thrown away  
the other day.  
Facing myself.  
No one else.  
The mirror was mine.  
Fell apart at the start.  
Cried tears to fast  
that wouldn't last.  
The feeling was mine.  
Now at home  
I'm all alone.  
Making my way  
day by day.  
The problem is mine  
all mine.



Organization for Understanding Cluster Headaches

## 1<sup>ST</sup> ANNUAL CLUSTER CONVENTION!!!

*NOW.....we are many!*

Monte Carlo Casino, Las Vegas

August 4 – 6, 2000

**RESERVE EARLY!!** Stay tuned to [www.clusterheadaches.com](http://www.clusterheadaches.com) for details

- Complete this application and mail it along with \$25 annual dues to -
  - OUCH 807 E. Broadway, Gladewater TX 75647

### O.U.C.H. Membership Application

Last Name	
First Name	
Middle Initial	
Street	
City	
Country	
Zip	
E-mail Address	
Phone	
Have You Ever Had Clusters ?	