



TRAVELING WITH CLUSTER HEADACHES

**BY Linda Howell (ex-Road
Warrior)**

The purpose of this article is to let you in on a little of my experience of being on the road with cluster headaches for the past 18 months. Most of it is common sense, but with cluster headaches, we sometimes don't have much of that.

The best thing I can say is BE PREPARED at all times. Your clothes and toothbrush can be packed last. Stock pile your meds if need be, but put them on your packing list first. Invest in one of those soft-sided coolers and put it next to you on your car seat. Filling it with ice for a cold pack for your head is no problem, but if heat works better for you, sporting goods stores have those little packages of hand warmers for campers. Also most restaurants, cafes, and short-stops have microwaves. Don't be shy about asking to use them.

I was on a flight from Miami to Los Angeles, out of Imitrex, and I felt the first twinges. I panicked! I dashed to the restroom and lo and behold – right below the sink is a high-flow vent of air that I used to breathe deeply for 15 minutes. I ignored the knocking on the door and was all right when I exited the restroom. Your crisis is JUST as important as anyone else's, but if you can, let the flight attendant know what you're doing.

Most of us want to be alone with our pain. In the car, pull over as quickly as possible, go to the nearest shady spot where you can be alone and if you need O2 and you're out (shame – shame) use the AC on your car to breathe. I've done this even in the cold winter.

There is no getting around the embarrassment one feels if you get hit with a 10 in public. If you can't get away and there is no time to explain what people are seeing right away, then you must rationalize

to yourself that you're spreading the word to the public about Cluster Headaches and heck... you'll never have to see these people again anyhow!!!! Happy Trails to You.

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SO YOU WANNA FIGHT ME? YOU WORTHLESS CLUSTERHEAD!

Dearest Clusterhead,

It has come to my attention that you are experiencing difficulties with your new or old found dilemma. That's all right. I intended it to be this way. Looking for answers? Surely you don't think I'll just let you brush me off so easily. I mean, give me some credit, I am the BEAST!

And let me tell you, I am not all pleased with your recent dealings with my other prey. Coming to this little site (ch.com)



Organization for Understanding Cluster Headaches

to find strength. Wipe that sheepish grin off your face too! What are you trying to get away with? These new friends of yours here are really starting to tick me off.

Maybe it would help you to understand why I insist you get away from them. You may think by my writing this letter, I fear the organizing of fellow prey? You forget my dear Clusterhead, I am the BEAST, and I will fight you at every turn! You see, I am not your typical foe. I am the master of disguise. May not to you, but to those around you. Look what I've already done to the majority of your doctors. I've clouded their minds. This is so easy. I have to laugh. I've convinced them what you're feeling just isn't so. I've trained them to suspect your problem lies in stress, allergies, diet, smoking, alcohol, head traumas, and my favorite of favorites, over reaction – Migraines, Tension or Sinus headaches. In fact, I love it when they treat you for these. It just cracks me up.

I know what you're trying to do here, but I can work in other ways myself to combat you. I can work on your friends, relatives, employers and coworkers. Sir Common Headache is one of my favorite allies. I don't mind his getting credit for my horrible deeds. Just the opposite in fact. The joy I feel when you cringe at the sound of them saying how they too have had had headaches. Oh what a riot! Excuse me, but one just sends me to the floor in uncontrollable laughter. Are you upset with me dear Clusterhead? I am the BEAST, I could care less how you feel about me, but don't you dare start explaining me to them!

Want to play games with me here? Fine. First go out and find that miracle drug that will cure you. Is it starting to work? Ooooooh... I'm melting.... I'm melting! Not! Yeah, it might work for a bit, but only for some and not always then. I can be a bit of a tease, but this is just too much fun. One of my favorite things to do is give someone just a taste of hope, let them yell out to the world how much better they are feeling, then pull the rug right out from under them and they are soon back. Call me what you will my

little Clusterhead. But you must understand I want Complete Control!

For me it's like a comedy channel. I like to tune in and watch the fun. My favorites are "Shove the Pepper Up Your Nose" and "Blue Cheese in the Mouth". Come on, go ahead, dance in the snow barefoot, drink like Michigan dry in a day, take hot showers, suck in that O2! Am I gone? LOL! naw, I may go for a snack, whilst this is going on, but I'll be back for the next show.

Hart to tell you how much fun this is for me, so get out of here and quit trying to rain on my parade! Oh by the way, I'm after your friend Kip. I didn't appreciate him giving you that scale for pain measurement. That was sly, but I'll find a way around it, you show too, tell me you had a 10+ or a 10++, heh heh, yeah that's the ticket!

Let the show begin! Go ahead, pace all over the place, not doing any good huh? Get on your knees and beg for mercy. Hmmmmm... still no good? How about squeezing your head as hard as you can? No? I didn't think so. Okay then, go head and try to hide, and while alone look at that wall ... yeah ... run your head into it. Come on, give it a few more shots, just for me. Floors are pretty hard too, how about a few head-bangers there? Ahh ... thank you. This is wonderful. Let's just do this for a while. Say 45 minutes to 4 hours? Thanks, that was sheer pleasure for me.

Now we must address a problem. What are you doing here among those who are trying to defeat me? Repeat after me, "No one knows the pain but me!" Come on SAY IT! Say it damn it! You are NOT listening to me!

I've told you to stay away from these people. I've told you to get away from that loving wife, that supportive husband. Don't let them try to comfort you. You are starting to make me angry. Okay then, you asked for it, take a shot of this! You should be ashamed of yourself. Look at what you are doing to them. You my Clusterhead are guilty, yes guilty! Feel it? Come on now, you must?



Damn! You need to quit sharing with all these people. Your numbers are growing rapidly here and now you also organize against me at OUCH. Damn all of you. This kind of sharing is not helping me in my cause. I can't deal with you learning to understand, accept and deal with me. Why are all these people trying to help? Am I not torturing them too? Why do they forget about themselves to help you? This isn't fair! I'm supposed to be in control ... oh please stay away from these groups. It's day-by-day making it harder for me to enjoy my work. It's getting tougher when you unite against. Me.

Damn you Clusterheadaches.com!
Damn you OUCH! Where is MY respect? I've got the rest of the world in my web, but you guys have to got stop this mutiny! I beg of you stop each other, stop understanding others, stop finding ways to laugh and stop finding ways to survive.

I'm the BEAST! I'm the ONE!

I'm the BEAST!..... I'm the Beast..... I'm the beast.....I'm the beeeastI a beeeessttt

**Ed's NOTE: This article was submitted by a prisoner of the Beast who has since escaped.

**MAY YOUR SEASON BE
BRIGHT AND PAIN FREE**

OUCH NEWSLETTER

**Contributors:Linda Howell
David Edmond
Barbara Henderson**

Profile: A Life of a Chronic Cluster Headache Sufferer



Author: Dave Emond

I would like to share a story with you of the life a chronic sufferer of Cluster Headaches. This is the truly amazing life of John Joseph Hallahan III ... no, he was not a millionaire castaway from the SS Minnow, but better know as Sailpappy to his fellow friends and sufferers in the Cluster Headache world.

Raised in Tampa, Florida, Sailpappy recounts memories of his childhood. "I remember the old oak tree lined road leading up to the general hospital where my mother ended up periodically because of Chronic Asthma and physical abuse suffered at the hands of my often drunk father." This abuse did not stop with his mother, but also to Sailpappy and his three siblings. This lead to him making a conscious decision, he would not become the carbon copy of his father, he would



never treat his future family this way, but instead with the utmost love he could give.

Illnesses were common in Sailpappy's family growing up, they were poor and had to pick up coke bottles to trade in for a meal. The constant fear of their father also made a lasting impact on Sailpappy: "I lived my whole childhood with this fact plastered just behind my eyelids, omnipresent and invading every decision I made."

Sailpappy was raised in the "Hippie" era and cranking out the tunes of the rebel bands like the Doors, Joplin, Hendrix and for us older ones, Moby Grape. However, Sailpappy also realized what turmoil was going on at that time in our world. He was beckoned to "do the right thing for my country", and joined the Army. He left school early on a GED, feeling the threat of Nuclear Proliferation was more important than class work. Soon, he would find himself in the middle of a war zone in Viet Nam.

Sailpappy went to Nam in 1969 for a guaranteed MOS being a UH-1H Helicopter Mechanic and a glorified door gunner. In his 4th month, he was shot down and forced to spend the night at an artillery Landing Zone called LZ Stinger.

"... while down for the night we were taking some heavy fire and they had to open up with 105 howitzers, one of them got so hot from firing so much that the barrel warped and the shell blew out the breach where you loaded the piece and ignited the ammo they had stacked around the cannon. This is the first Cluster Headache I am conscious of; in the weeks and months that ensued I began having them more and more often, until I was up to about 7 a day, every day."

As the author of this story, and a fellow sufferer, I can't help but read this statement over and over. Everyone remembers their first CH attack, but this visual will be imbedded in my mind forever.

Now of course the Army was not about to understand or properly treat Sailpappy and his strange disorder, so they pumped him with a quart of codeine and sent him back to duty!

Numerous trips to sick call, from the pain and complete lack of sleep, went nowhere for our friend. A bunk mate, "Cal", was a heroin user and said to him, "John just take one hit of this and I'll guarantee it will stop your headache." (Considering the time and events, I ask ... who wouldn't?)

Sailpappy: "Well Cal was right, not only did it stop my headache, it stopped everything, every type of pain I had was gone and sleeping was never a problem again. In fact, I would fall asleep at the most in opportune times that it became dangerous and I got grounded from flying. Put on what they called the First Sergeants Detail. I had 50 days left and got myself put on the list of the most expendable people in the company. Morning would be the surprise of the day's assignment, go out with the infantry guys, fly scouts, do foot recon or whatever they needed someone to do because it was a suicide mission. I made it and brought my Monkey back to the states with me ..."

Having to deal heroin to support his new habit, Sailpappy and some friends decided to rob a gas station. Fortunately, he changed his mind at the last moment and was dropped off at a local hospital where he turned himself in. His friends went on to rob the gas station and in the process killed the clerk, and are all doing life in Levonworth Military Prison. Sailpappy decided to go clean, and through the withdrawals, the Clusters resurfaced. In March of 1971, the Army arranged for him to get a dishonorable discharge, taking away his VA benefits. But Sailpappy was earnest in his search for treatment for the clusters. Finally after three years of fighting, he received enough of a disability rating that he could get all of the medical assistance he needed. He was able to hook up with an ENT who had been President Carter's specialist while he was President and then sent to Orlando Clinic after that term.

The list of medications and treatments was endless. Prednisone Therapy over and over and Verapamil were promising for about 6 months. He spent the next 10 years working with Glaxo Corp, consulting with Dr.



Diamond and Dr. Matthews, but the first injection resulted in the worst hit of Angina that he had ever had.

Sailpappy: " So in 1989 I gave it all up for the holistic approach, I took no meds at all and exercised like there was no tomorrow, took mega doses of vitamins, I swam everyday and by the end of the year I was doing a 7 mile swim while pulling my daughter and at least one, but most often two of her friends in the boat too!" The repetitive exercise at first bored Sailpappy to tears, but by mixing the exercise program with making these children's days exciting and fun made it important and worthwhile.

It would be 10 years later before the Clusters got to the point where he couldn't handle them any longer, 10 to 15 attacks a day and a terminal illness on top of it left him very empty and in pain beyond explanation. Then he found Clusterheadaches.com, " ... probably the best thing that ever happened to me ... through the relationships I found there I was able to endure a host of horrific events that occurred in my life, made it through the year of Chemo (Failed) and am still here raising my 2 wonderful Grand Kids ... I enjoy every serious relationship that has spawned from Clusterheadaches.com, I really love all the people there and I feel like I have really achieved something if I read where someone actually benefited from something I may have contributed."

I'd like to stop here for a moment and add a note that I believe shares the opinions of all who have met or talked with Sailpappy. His posts and letters are honest, polite, and positive and have the highest level of integrity. Sailpappy ... John Joseph Hallahan III ... has indeed been an inspiration and many have indeed benefited from his contributions. I'm sure without hesitation, we could all in unison say thank you for your strength, friendship, loyalty and wisdom you have brought to us all.

I wish I could do pages on the amazing life of this man, he has shown that through the greatest of trials, one can still claim victory over life's obstacles and instead of giving in to his own battles, he chooses to help

others. This is one look into the life of a Chronic Cluster Headache Sufferer.

For those who don't understand Cluster Headaches and the inhumanity of the pain associated with this disorder, please understand this, here is a man who fights each and every day. Not only for himself, but also for his family and fellow sufferers. Please consider visiting clusterheadaches.org for more information on how you to could help "Sailpappy" and others fight this horrible disorder.

Sailpappy today has the loving support of his wife of 29 years, Teresa Lee. Three children, James, Bryan and Amanda. And, five grandchildren, Heaven, Trysten, Chasten, Ian and 2-month-old Connor.

Recently Sailpappy had four heart attacks and had to have angioplasty, he is feeling well now. He has had to return to medications for the Cluster Headaches, and at the time of this writing is experiencing some long overdue time of being pain free. We could hope for nothing less than for this remission time to continue forever for one of our most beloved friends in our Clusterhead family.

I consider it a privilege and an honor to have introduced you to our sincere friend ... Sailpappy!

**HAPPY HOLIDAYS
TO ONE AND ALL**

**May the season bring pain free
days to each of you**



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