

Hot Time At Atlanta's O.U.C.H.'s 2001 Convention

Barbara Henderson

Conventioneers began descending upon Atlanta, GA on the Tuesday before the Organization for Understanding Cluster Headaches' (O.U.C.H.) June 26-July 1 convention was to begin. By Friday, most of the 50 attendees already arrived and were established in the Holiday Inn ready to greet the "late" arrivals with hugs and kisses.

Attendees registered in the lounge where it seemed 50 different conversations were taking place at once. Some conventioneers went from the lounge to the hospitality suite with regularity. It was confusing at best, but no one seemed to mind.

Dinner was at

Shoney's restaurant, a short stroll from the hotel. There was a lot of getting to know each other, renewing friendships from last year and, of course, talk of clusters. Then back to the hotel hospitality suite with more. In fact, most of us didn't sleep much on Friday night. We spent it talking until quite late.

Saturday morning came early. The convention officially began at 8 A.M. (the first vote of the day was to shoot whoever set the time to start the convention at that ungodly hour!). Since President Dave Greenly was not present and VP Bob "Kip" Kipple's wife was ill, requiring him to be in and out during the day to check on her, President-elect Bob Pahlow officially took charge of the convention. Commendations go out to Bob for his handling of this job. He did it well. And a special thanks to his wife,

Sarah, for taking the meeting's minutes since our secretary was also absent. Committee members gave their reports, and suggestions for future O.U.C.H. work.

Several new committee chairs were named who gave their ideas on what they intended to accomplish year's end. First was Leesa Dobson who became Membership Chair and who intended to at least double our membership. Before the convention's end many who weren't members when they arrived were when they left. The lady is off to a good start.

John Graham, from O.U.C.H.-UK, spoke on what their chapter accomplished since January, including fund

raising, membership building and how they've gone about both.

Treasurer Barbara Henderson reported on the good state of our finances. As of May 31, O.U.C.H. had a balance of over \$9000. T-shirt sales were going great. Donations were up from last year. Dues were up from last year. And the convention was right on target within the budget set out. She stated she would be presenting a recommended budget for the next two years at the Board of Directors meeting during the luncheon board meeting. The books were left (*Cont'd p. 6*)



Clusterheads attending seminar on suicide and chronic pain.

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Suicide: It's Not Just For Attention Anymore

Nancy Collins

"Oh I wish I were dead!"

"I think I'll just shoot myself!"

"I can't stand this anymore, I think I'll just kill myself!"

How many times have we heard these expressions and ignored them? Too many times to take them seriously? If someone is really going to commit suicide, they're not going to *tell* you about it in advance, right? What can we do if someone is really serious? After all we're not trained professionals, right?

During a seminar on suicide at the Organization for Understanding Cluster Headaches' (O.U.C.H.) convention in Atlanta this June, we got a different view of suicide, especially where it concerns cluster headaches, and several signs we all need to be watchful for in ourselves as well as others:

Warning Signs of suicide:

- Change in sleeping patterns (sleeping more or not as much)
- Change in appetite or weight
- Agitation or enraged behavior
- Excessive alcohol or drug use
- Loss of interest or pleasure in usual activities
- Decreased sexual drive
- Fatigue or loss of energy
- Feelings of worthlessness, loss of self-respect or guilt
- Talk of suicide
- Speaking or moving with unusual speed or slowness
- Diminished ability to think or concentrate
- Slowed thinking or indecisiveness
- Thoughts of death, suicide or wishes to be dead.

When a person begins exhibiting at least five of these signs daily over a period of two weeks it's time to become concerned and start looking for help for that person. The key to preventing suicide is detection and treatment.

Those of us who suffer from cluster headaches know about pain and how it can cause depression. If you suspect that someone you know is depressed please encourage them to get help. There are a wide variety of antidepressants available as well as other help for depression. But always take the threat of suicide seriously. You may think these threats are just a bid for sympathy or attention, but you could be dead wrong.

For more information on suicide got to O.U.C.H.'s crisis-intervention page at:

http://www.clusterheadaches.org/crisis_intervention.htm

Cluster Art



Cluster Headache Corner Artwork by JD



Cartoon by JD

Visit the [O.U.C.H. Online Store](http://www.clusterheadaches.org/store.htm) for all your gift needs.



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

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?	

Send \$25 membership fee on a check drawn from a US bank to OUCH, 807 E. Broadway,
 Gladewater, TX 75647

Help for Supporters! <http://www.clusterheadaches.org/family.htm>

Profile: Living With Clusters Headaches In Italy

Dave Edmond

For those who know of cluster headaches, it's hard not to wonder about the lives of those who are victim to this rare disorder. I'd like to tell you a story about one such victim and his life in dealing with this adversity.

The year is 1953, and the place is Torino, Italy. Torino, "The City of a Thousand Faces," welcomed one more new face. One who would be a beacon for many in the future. Riccardo Pentenero grew up in this city, which grew as quickly as he. As a boy he walked the tree-lined avenues, the great squares and luminous internal courtyards in one of Europe's greenest cities.

At 22, he moved on to the smaller nearby city of Pinerolo. He got himself a job playing piano at a riverside bar. There were three institutes for women in Pinerolo, so there's not much surprise why Riccardo would end up here. Imagine the humidity and fans in the hands of the women as they leaned on his piano and whispered "Play it again Ricky."

After closing time, Riccardo would go home to find an uninvited guest. It was the Beast. It was a CH. Being new to this pain, Riccardo did as so many others have done; he lay in his bed hoping for the pain to go away. His first three years he considered mild with two attacks each night of his two-month cycles lasting 2-3 hours each. Sad to think this was considered just *mild*.

For the next eighteen years Riccardo suffered the full fury of episodic cluster headaches. Three or four attacks per night: 12 PM, 2 AM, 4 AM and 30 percent of the days at 6 AM. All in full force lasting at least an hour. If that weren't enough, every odd day Riccardo would get hit in the afternoon. Maybe the attacks were not with full force, but for longer periods of time.

Then there was a period when they switched from the right side of his head to the left. This torture went on for a month, and was the worst he ever felt. Riccardo was in his forties before he was able to start finding effective

medications. He found a good neurologist who worked with him, trying Verapamil, tricyclics, antidepressants, Imitrex and Paracetamol.

The Imitrex did nothing for Riccardo. The Paracetamol would slightly reduce the severity and length of an attack, which comforted him just a bit. The Verapamil could stop a cycle only if taken ahead of the cycle starting. Oxygen provided no miracles for Riccardo either. It only lessened the effect of a full-blown attack. He never found a medication that helped him completely but only lessened the pain a bit.

So, Riccardo started his own battle. He always kept windows open at work and at home ("Go figure the happiness of my colleagues," he joked), never stayed in crowded rooms and tried to take care of any sinus infections at their first sign.

In the meantime Riccardo found a message board at www.clusterheadaches.com.

"I immediately fell in love with the people. I cried and laughed and was (*cont'd p. 6*)



Left to right: Elena, Marina and Riccardo



Riccardo Cont'd.

astonished at the discovery of *how many* are like me. I am sure this is one of the better things that happened in my whole life. Help, friendship, laughter and information. I do not swear that helped me. I'm not sure, but I'm in remission from that. The fear still exists, and is a good thing, I don't want to claim to myself I'm out of the tunnel. But I'm happy. Every end of January I make a great, happy dinner with my family, in honor of the Demon."

His biggest hope is that a cure for the syndrome is found. "I'm scared of the possibility of inheritance for my daughter. Secondly for myself (leaving remission), and for all the people I know and don't know with this Beast. Especially for the chronics, I cannot imagine a life with this thing." For those who know Riccardo, I don't have to say much about what he means to all of

us sufferers. For those learning about CH and those who live with it who don't know him, Riccardo is a man respected by his fellow victims. He speaks often of his wife Marina, and their daughter Elena. He has never allowed his daughter to see him under attack, and his wife understands his preference to be left alone during them. With Riccardo in a four-year remission, he has not forgotten others in need. He continues to support the Organization for Understanding Cluster Headaches (O.U.C.H.) and is a member of their Board of Directors as well as a candidate for the organization's vice presidential position. He is equally as supportive with fellow sufferers. CH victims are not weak or intolerant to pain. If you take the most painful disorder known and take a look at people like Riccardo, you'll see that they can indeed be some of the strongest people you'll ever meet.

Convention Cont'd.

open for anyone to look over, as mandated by nonprofit corporate laws.

The BoD held a meeting during lunch and voted for several items. Among them were: Putting legal counsel and a CPA firm on retainer; Holding convention 2002 in Vancouver, Canada; and opening an online store to sell O.U.C.H. items.

The afternoon session began with a speaker talking about suicide (See page 2). She began by explaining the whys and what-to-watch-for, but quickly learned that we were familiar with the signs so it soon turned into a what-to-do-to-help session.

Finally, banquet time arrived and although it signaled the ending of the convention, everyone was lively and had a great time. Awards were given to those who went above and beyond the norm since O.U.C.H. began. A group picture was taken of all attending clusterheads and then Bob Pahlow officially adjourned Convention 2001.

But, some of us weren't ready to quit just yet. We spent Sunday talking and planning what to do when we got home. And of course saying goodbye, which was the hard part. We had to say goodbye to those who were leaving – those people who had been strangers just a few days ago and were now so dear to us, were leaving. There were a lot of tears and "See you next year," and "See you on the (CH.com) message board," and a lot more tears.

For the ones who didn't get to attend convention, you missed a wonderful experience of getting to know those who did. When clusterheads get together there is a bond that is formed that is indescribable. For those of you who were there, see you next year in Vancouver.