ON-CAMERA HOST: ESTABLISHING SHOT

ON-CAMERA HOST
Work. Family. Activities. Chores. Life can be challenging. If you’re a person who experiences the debilitating pain of cluster headaches, then you understand how days and nights can be shattered; how those everyday challenges can be magnified.

Although rare, cluster headaches cause severe pain that comes on quickly- often hitting a peak in just 10 to 15-minutes. With each attack lasting from one to three hours on average.

PAUL REVAY:
When you’re in the cycle you know you can’t go too far from home because when they hit, you certainly can’t drive.

JOHN MILLER
When the cluster headaches do come on, you have to stop what you're doing and either take treatment or just wait it out. And a lot of times the waiting out is when you can’t concentrate. You can’t focus on your job.

ON-CAMERA HOST
Cluster headaches often begin with a sudden onset of pain on one side of the head, usually behind or around the eye. As pressure builds, other symptoms such as red or watering eyes, stuffy nose, drooping or swelling of the eyelids, flushed skin, sweating and restlessness can occur.

01:31

DR ROBERT KIENICKI
The most important symptom of cluster headache is the headache. It is described by many as excruciating. And typically, it's forehead, eye socket, temple, and described as a boring, searing, burning pain. Patients having cluster, they compare it to migraine, kidney stones, gall stones, childbirth, will say universally that cluster is the worst pain they've ever experienced.

JOHN MILLER
I start feeling a sharp kind of stabbing pain that, it's kind of right behind my eye.

PAUL REVAY
You get nauseated. You pace. You do anything. I mean, you'll curl up in a fetal position. You'll rock. Sometimes I used to just drive my thumb into upper part of my eye, just so it hurt worse than my head hurt.
JOHN MILLER
During that time, if the headache is still at its peak level, I end up just walking and pacing the floors. 02:27

ON-CAMERA HOST:
While cluster headaches are not life threatening and won’t cause permanent brain damage, they are often chronic and can occur every day up to multiple times a day over the course of months or years.

DR ROBERT KIENICKI
Well, cluster headache follows two main distinctive patterns. One is episodic cluster. That means that for the most part over the course of a year, you have more headache free days than headache days, simply put. Chronic cluster, one out of 10 patients have chronic cluster, where during the course of a year, they'll have more days with these headaches than without.

JOHN MILLER
I have the type of headaches where I have a period of completely cluster free or completely no headaches during that time period. And that could be anywhere from two to three years.

PAUL REVAY:
Well, when the cycle's going, it's basically, you might only have one headache a day, but you can have up to eight to 10 a day. And until you're at least four days free of headaches, you can expect that you're going to keep having them.

ON-CAMERA HOST:
Although researchers haven’t yet determined exactly what causes cluster headaches, they have been able to conclude that they are often related to a sudden release of histamine or serotonin in the body and may also be triggered by a number of other factors.

DR ROBERT KIENICKI
For years, we know what part of the brain malfunctions during cluster, and it's the hypothalamus. It's the internal clock. So, we know where, and we've known for oh, 15 years now. We don't know why. We don't know why men. We don't know why smokers. We don't know exactly why those factors predispose people with cluster, or why it's more younger to middle aged adults and not the very young, or perhaps the elderly that start up with these.
ON-CAMERA HOST:
Triggers and symptoms may vary, but those who live with cluster headaches often experience changes in alertness, loss of movement or sensation in limbs, nausea and vomiting, changes in vision and seizures. Signs like these are key indicators that it's time to reach out to your health care provider.

JOHN MILLER:
I think it's very critically important to seek out a specialist in the field, whether it be neurosurgery or a headache specialist, because they're the ones who see this day in and day out. And that's what changed for me when I was able to go from my primary physician to the next stage. And then I was able to find, get the proper diagnosis, but also get the proper treatment.

ON-CAMERA HOST:
If you experience Cluster Headaches, know that today... there is hope. Research continues resulting in new drugs and strategies specifically designed to target cluster headaches.

DR. ROBERT KIENICKI
The future of cluster headache is much brighter than the past has been. I wouldn't necessarily use the term the dark ages, but we've exited a time where we didn't know much about cluster at all, and we certainly didn't have any good treatment options. But it's also challenging because the number of treatment options we have are still short of the mark. The research though in this is really exciting.

JOHN MILLER
Treating cluster headaches is definitely a work in progress. There's a lot of trial and error involved in figuring out the right form of medication to take, but also to help prevent the cluster headaches, what to take to abort the cluster headaches when they actually come on.

ON-CAMERA HOST:
To help you prepare for a meaningful conversation with your healthcare provider, The American Chronic Pain Association has created this Cluster Headache Conversation Guide. It's available on the ACPA web site. Simply print it out and complete each section before your appointment so your provider can have a clear understanding of your individual symptoms.

DR. ROBERT KIENICKI
... it's really important to come prepared and to be very organized. And that can be the visual of seeing them on a calendar, and then it's also the visual of coming in with these graphics where somebody, their eye is bloodshot, or they're holding that side of the head, something like that, that can help the doctor, clue in and say, "Oh, yeah, I think this is what you've got."
JOHN MILLER
My life has changed much better for the better now that I have a diagnosis and know how to treat it and I'm in the hands of a good medical caregiver who understands the issue as well.

PAUL REVAY
It feels excellent to get back to the world of being normal, like I was previous years where you never even gave a headache a thought.

ON-CAMERA HOST
The task of dealing with cluster headaches may seem daunting, but it IS possible to regain control. It begins with an informed conversation with your health care provider, discussing your experience, developing a treatment strategy, and then putting it into action. With patience, persistence, and a plan, you CAN get your life back.