

A Punk Rock Icon Takes on MS

Outspoken singer and artist Exene Cervenka brings hard-earned optimism to her struggle with multiple sclerosis.

BY TODD FARLEY

or a punk rock icon, Exene Cervenka isn't much of a nihilist. In fact, when the co-founder of the seminal Los Angeles band X was diagnosed with multiple sclerosis (MS) in May of 2009, Cervenka didn't allow herself to become negative at all. The singer was familiar with the disease. As a teenager, she solicited funds for the National Multiple Sclerosis Society. As an adult, she raised money and awareness for Sweet Relief, a charity started by MS patient and singer Victoria Williams that aids uninsured musicians. (See "Bittersweet Symphony," July/August 2009, at bit.ly/bH23NL.) But even the spooky irony of those experiences wasn't enough to get Cervenka down.

"I haven't changed my plans," she says, in true punk style, "and I don't intend to."

Cervenka, born Feb. 1, 1956, received much musical acclaim in the late '70s and early '80s when her band, X, led the California punk movement of that time. Songs like "Los Angeles," "The New World," and "I Must Not Think Bad Thoughts" became underground classics. (Little known fact: Many rock critics believe Madonna's early look was lifted from Cervenka. The Material Girl's style of thrift-store duds and arm bangles was surprisingly similar to what Cervenka regularly wore on stage.) The 1981 X album *Wild Gift* was named *Rolling Stone*'s Record of the Year. Cervenka has since played with a number of other bands (The Knitters, Auntie Christ, Original Sinners) and worked as an author, artist, and teacher.

DEFIANT SPIRIT

For Cervenka, the road to a diagnosis of MS was long and often frustrating, filled with what she refers to as a host of "strange, undiagnosed illnesses." She experienced her first MS symptom—blurred vision in one eye—in 2000. Her doctor

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referred her for an MRI but the test came back inconclusive. Cervenka wanted to undergo a lumbar puncture (also called a spinal tap), which at the time was a standard test used in the diagnosis of MS. However, the singer had to postpone the test because she was scheduled to go on tour the next day. When she returned she was no longer symptomatic.

"By the time I got back, six weeks later," Cervenka says, "they thought that it wouldn't really be an accurate test."

The blurred vision went away, and Cervenka felt fine "for a long time." Even though she had some symptomatic episodes involving confusion and severe headaches, the singer says she wasn't initially aware of what the episodes meant or that they were indicative of MS. But by 2004, the recurring symptoms—along with the knowledge she gained about the disease when her friend Victoria Williams was diagnosed in 1993—led Cervenka to suspect that she too was suffering from MS.

"Before I went to the doctor in 2004 I was sure that I had MS," Cervenka says. "But again my MRI was fine, so they thought I was just a hypochondriac."

Today Cervenka realizes that many MS patients have had the same feeling. "A lot of people with MS are familiar with that diagnosis of 'there's nothing wrong with you—it's all in your head."

A diagnosis of definite MS, which can be difficult to make, requires the following: The person must experience at least two symptomatic episodes (more than a month apart); the two episodes must be due to damage to two different parts of the nervous system, which includes the brain, spinal cord, and optic nerves; and all other possible diagnoses must be excluded. Neurologists rely on extensive medical histories from patients to determine the number of episodes, and whether the symptoms they experienced were likely to be in different parts of the nervous system. A number of tests can help in excluding other causes for the symptoms and providing support for the diagnosis of MS. Brain MRIs in patients with MS typically show lesions in the connecting fibers (the white matter) of the brain, optic nerves, and spinal cords. Lumbar punctures in MS patients are done to look for high levels of immune system activity. (Normally, immune system activity is very low or absent in healthy people.) But sometimes the tests are inconclusive, and occasionally patients can go undiagnosed for years after the initial onset of symptoms.

Cervenka's diagnosis occurred in 2009, when in March she experienced the onset of severe symptoms. "I couldn't think, walk, talk, do anything," she says. "I was a passenger in a car, going down the highway, and suddenly there was two of everything for an hour and a half. I knew, as soon as I got home, that I had to go see the neurologist right away."

When she saw her doctor and underwent tests again, the



lumbar puncture came back normal, but her MRI did not. "That was the third MRI," Cervenka says. "I was positive I had it. They just kept saying no, but I knew."

Her defiant spirit and determination to listen to her body paid off. On May 4, 2009, in the midst of a symptomatic episode, Cervenka was finally diagnosed with the most common form of MS: relapsing-remitting. Patients with relapsing-remitting MS experience symptomatic attacks followed by periods of remission. Suffering from vomiting and severe headaches, Cervenka wound up hospitalized and received steroid infusions over the course of three days.

"I was very sick and very weak," Cervenka says, remembering what she refers to sarcastically as her "Welcome to MS Day." Despite how sick she was at the time, Cervenka says she felt relieved to receive the diagnosis. "You don't want there to be anything wrong with you, but you want some sort of treatment if there is."

NO MIRACLE

While there is still no cure for MS, drugs are available that can help modify the course of the disease, treat flare-ups, and manage symptoms. Interferons (such as Interferon Beta 1a and Beta 1b) have been shown to decrease relapses, while glatiramer acetate is a mixture of four amino acids that has been showed to slow progression of the disease. All are injectable drugs. Several MS medications in pill form are also available now, including the recently approved dalfampridine. (See "Oral Drugs for MS," May/June 2010, at bit.ly/cgCo15).

"It used to be that about 50 percent of people, about 15 years after diagnosis, would be using a cane or some type of assisted walking device, and in 25 years, about 50 percent of people would be disabled." Dr. Jung says. "But that was before we were able to modify the disease with current medications. The good news is that people are no longer destined to life in a wheelchair."

Cervenka takes glatiramer acetate to help slow the disease and to decrease the occurrence of symptom relapses. She says that while she is relieved to be on a medication that helps suppress flare-ups of symptoms, "You can't say that because you're on it, you're not going to have any symptoms. There is no miracle drug."

Miracle drug or not, Cervenka is determined to continue working as an artist and musician. She has written a number of



books, recorded a spoken word CD, and had exhibitions in Los Angeles and New York of her "found art" collages. Cervenka used to create the collages out of "stuff I found on the street, but America's garbage has changed in the last 30 years. Now all you find are McDonald's wrappers," she says.

Not surprisingly, an outspoken artist like Cervenka isn't shy about stating her opinions. "I think diseases of the immune system are largely environmental," she says.

In addition to genetics, environment and lifestyle play a role in most diseases. As Dr. Jung notes, "Things that keep your immune system in check are good, like getting enough rest and eating healthy. These things that can help your disease and maintain your overall health." Michael J. Zigmond, Ph.D., professor of neurol-

ogy at the Pittsburgh Institute for Neurodegenerative Diseases, echoes those thoughts, stating his belief that everyone would be healthier by avoiding the "toxic lifestyle" of modern life, which includes poor diet, too much stress, and too little exercise.

Since her diagnosis, Cervenka has altered her lifestyle in order to create a healthier environment. She maintains an almost completely vegan diet, exercises frequently, takes vitamins and supplements, and practices yoga.

"I'm taking such good care of myself," she says, "I'm a healthier person. On some level, I don't feel sick at all. I feel very lucky to be alive."

Cervenka also attributes her sustained health to the "outpouring of love and support" she has received from family members, friends—even complete strangers. "I've met amazing people. I think one of the blessings of having a condition like this is the opportunity to meet people with MS and other illnesses. The advice and help they've given me offers a whole new perspective on life."

The decision to go public with her diagnosis was an easy one for Cervenka to make. As a performer and celebrity, she knew she had to tell everyone she worked with. She felt a professional responsibility to tell her agent, who had

Thanks to **disease-modifying treatments**, "people are no longer destined to life in a wheelchair."

-LILY JUNG, M.D.

to tell the people who were booking Cervenka for performances.

"You can't keep that information from people. I told friends, and friends are gonna tell friends," she says. "The announcement of my MS was probably the most coverage I've ever gotten," she jokes.

Cervenka also chose to share the diagnosis with others because she wanted people to know that she was going to be positive about it. "Being positive is the only choice for me. I believe that with medication, lifestyle choices, and lots of love, I can live a full, happy life."

But her determination to live a full life is tempered by a realistic attitude. For many years, Cervenka has worked as a musician, writer, visual artist, and performance poet, and she concedes that she might have to give up one or two of those things. She does not, however, intend to give them all up.

"I'm going to keep doing my art," Exene Cervenka says, "because that's my life."



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Multiple Sclerosis: The Basics

ultiple sclerosis (MS) damages the myelin (the protective sheath) surrounding the nerves that transmit messages from the brain to the spinal cord. This damage is caused by an inflammation of the central nervous system that results in lesions, or scarring, in the brain (the term "sclerosis" means scarring). Multiple sclerosis can also damage the nerves themselves.

"When the nerves are damaged," says Lily Jung, M.D., director of the neurology clinic at the Swedish Neuroscience Institute in Seattle, WA, "there is a resultant loss of brain and spinal cord neurons, so MS is considered neurodegenerative, like Parkinson's or Alzheimer's."

According to the National Multiple Sclerosis Society, approximately two and a half million people around the world suffer from MS. The causes of the disease are largely unknown. It's common for the onset of symptoms to begin between 20 and 50 years of age, although the disease can appear in any age group. According to Gary Birnbaum, M.D., director of the Multiple Sclerosis Treatment and Research Center at the Minneapolis Clinic of Neurology, "About two-thirds of the people with MS are women and one-third men. It occurs predominantly in people of Northern European origin, and there is a certain genetic predisposition to it." Interestingly, MS is seen less frequently in people living closer to the equator, although researchers aren't sure why.

When MS impedes the transmission of messages between the brain and the spinal cord, symptoms of the disease such as difficulty with motion, vision, and balance occur. People may experience intermittent feelings of dizziness, numbness in the hands or feet, tremors and/or weakness in the arms or legs, muscle spasms, double or blurred vision, fatigue, and difficulty with speech.