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Dangerous Side Effects

By Jill Kramer

Special Forces medic Bob Rogers is used to toughing it out in grueling physical circumstances. In the first Gulf War and in Afghanistan, he served in 115-degree heat without enough sleep, water or proper nutrition. Feeling good was never an option. For months after returning home two years ago, he still didn't feel right, but he didn't dwell on it. His wife however, was finding him impossible to live with. One day they were arguing and she poked him in the chest with a finger. And Rogers did something that terrified both of them.

"I don't know what happened for the next few seconds, but I heard my daughter scream and I found myself with my wife backed into a corner, hitting her. I suddenly realized what I was doing and I was like, holy shit! I immediately called TriCare mental health division and asked for help," he says. "This is something that I despise. I detest people that beat women. I've always been that way. So for me to do that, it's a complete loss of self-control."

Several more months passed before Rogers figured out what was wrong with him. He was reading a Gulf War Web site and saw an item about Lariam, the anti-malarial drug he'd been given in Afghanistan, which listed side effects ranging from dizziness to psychotic behavior. "I think I had almost every one of those symptoms. They'd been there for some time but I just didn't recognize them." Rogers says it's not unusual for Special Forces Type A personalities like him to ignore their ailments. "I used to do 100-mile marathons and stuff like that – it's not real easy for me to come to grips that there might be a physical problem I can't overcome."

Rogers, who asked that his name be changed for this story, is one of a group of service personnel diagnosed this year with Lariam-induced brain damage. Veterans' advocates say these cases are the tip of the iceberg. The risks of the drug have been historically under-reported, but it's been known for years to cause a laundry list of physical and psychiatric problems in some people. For that reason it's fallen out of favor with informed business and pleasure travelers, although it's still prescribed by many physicians. The Peace Corps still gives it to volunteers and the Centers for Disease Control still considers it an appropriate drug in some malaria-infested areas. The Department of Defense has recently ordered that Lariam be replaced with a different drug for soldiers in Iraq; but there are reports that it's still being used there, as well as in Afghanistan. And soldiers like Rogers are still wrestling with side effects that the military bureaucracy is slow to recognize.

The fact that the military has begun moving on the problem at all is due largely to the work of two women. Sue Rose [Silver Spring, MD] and Jeanne Lese [San Rafael, CA] have been running Lariam Action USA since 1996. They've been drumming up press coverage, consulting on litigation against the drug manufacturer and working with Senator Dianne Feinstein's office to bring the issue to Congress. This spring, Feinstein sent a series of letters to Secretary of Defense Donald Rumsfeld and department heads in Veterans Affairs, Health and Human Services and the Centers for Disease Control pointing out the dangers of Lariam and urging action.

Jeanne Lese is outraged that troops were ever given the drug, and she's convinced that they're still forced to take it. "The fact that the military continues to reserve the right to use this drug whenever they see fit is absurd," says Lese. "It says right on the label that it should not be used by pilots or people operating heavy equipment because it can affect eye-to-hand coordination. Why the military would ever choose to give a drug that screws up your eye-to-hand coordination to people carrying guns is totally beyond me."

The kind of episodic rage that overcame Rogers is also reported by other soldiers. As far back as 1993, Lariam was cited when a Canadian peacekeeper beat a 14-year-old Somali boy to death. Two years ago, it was a factor in the cases of three soldiers, back from Afghanistan and stationed at Fort Bragg, who killed their wives and then themselves. Now facing trial are three soldiers who shoved two Iraqi civilians off a bridge into the Tigris River, where one of them drowned.

"I don't know if Lariam is connected to the crimes of these gentlemen, but the product insert clearly says that these are some of the side effects that can occur – rage, irrational thought, homicidal and suicidal ideation," says Steve Robinson, former executive director of the National Gulf War Resource Center, who was called as an expert witness in the case. "I do know that the unit these soldiers were in was issued Lariam because every soldier I talked to in the unit said they were."

Other symptoms of Lariam toxicity include loss of balance, memory and concentration difficulties, visual disturbances, seizures, hallucinations and paranoia. How many Lariam takers experience these symptoms is the big question. Estimates are all over the map. The drug manufacturer (Hoffmann La Roche), the Department of Defense and the Centers for Disease Control characterize serious side effects as "rare." A 1996 study found serious side effects at a rate of one in 140. A 2001 study reports moderate to severe symptoms in 19 percent of travelers. And a 2003 study puts the rate at 42 percent.

"I go to the World Travel Health conference every year and every single year, as far as I can remember, there's always a debate regarding Lariam," says Dr. Joseph Habis, a travel medicine and tropical disease specialist based in San Rafael. "Entire lectures and whole committees have been formed on the use of Lariam. It's been a very hot debate between the Americans and the Europeans. When I was traveling around the world in 1994, a lot of Americans were taking Lariam and all the Europeans would say, 'Oh, we wouldn't touch that stuff.'"

From his reading of the literature, Habis believes neuropsychiatric symptoms show up in 15 – 30 percent of Lariam users. Although he rarely prescribes it now, Habis used it frequently in past years. "It was popular here in the states in the '90s and at that time it had the best efficacy rate of

all the other anti-malarials. And it's a once a week regimen, so it's a little easier to take. We've learned a little more since then about the side effect profile."

Some of his patients reported problems, but Habis isn't certain the drug was necessarily responsible. There were patients who came back saying they had perception problems, visual problems or difficulty concentrating, anxiety symptoms. Whether they were related to the Lariam was difficult to say. I've never had any patients suffering long-term effects of Lariam that's clearly described in the literature."

Sue Rose of Lariam Action USA thinks that part of the difficulty in tracking the frequency of side effects is that patients don't report their problems to the prescribing physician. "You go to a travel doc to get your meds, you take off, you come back sick as a dog, you don't go back to the travel doctor. So the travel doctors are saying we're not seeing any problems but they're not doing any follow-up care," says Rose. "And if you think you've just flipped out, you're not going to call up your GP and say that drug you gave me made me feel really weird. That's been the whole problem."

What's more, when doctors don't warn their patients about specific side effects, the patients won't necessarily associate their symptoms with the drug – particularly if their symptoms are emotional or psychological. Before Sam Snyder, a Bay Area resident, went to Cambodia three years ago, the only potential symptoms his doctor warned him about were nightmares. So when he started feeling anxious and paranoid, he blamed it on the unfamiliar environment. When he experienced a rapid, irregular heartbeat, however, he thought he was having a heart attack and went for medical treatment.

Snyder, who asked that his name be changed for this story, had gone to Cambodia to oversee a hospital project. He described his symptoms to a nurse there who was familiar with Lariam and she asked him if he was taking it. When he told her he was, she said, "Stop taking that immediately." A few days later, his symptoms were gone.

But Snyder's troubles were only beginning. Six months later, back home, he began having balance problems. "I noticed that when I turned my head, I had really hard time maintaining my balance," he says. "It's like being slightly drunk – all the time. I'm constantly dizzy. The world is not the way it was." Snyder was worried about his livelihood. Newly married and with a baby on the way, he worried most of all about safely holding his child.

He went to an eye doctor and was told his eyes were fine. He went to an ear specialist and was told there was nothing wrong. He had an MRI and was told he didn't have a brain tumor. Each time a doctor sent him away telling him he was "fine," Snyder became more and more desperate. "*I'm not 'fine'!*" he kept telling them. It wasn't until his sister stumbled upon the Lariam Action USA Web site and told him about the symptoms that he understood what was wrong and was able to get physical therapy.

Jeanne Lese is well aware that the Web site serves as a lifeline to many. "Some of these people don't have anybody else to talk to," she says. "Nobody believes what's happening to them. Their

doctors don't believe them. They're told it's all in their heads." Lese appears to be the unlikeliest of activists. She used to be an English teacher at a women's college. She married a researcher at Gulf Oil and quit work when the first of her two children was born. The Leses moved in 1985 to a tidy Terra Linda neighborhood near the high school, where they've lived ever since. After the children were grown, she went into marketing and public relations work; and it was those PR skills that attorney Sue Rose needed for the fledgling Lariam Action organization. The more Lese learned about the drug, the more dedicated she became.

For the last several years the two women have been funding the operation themselves. "We were so involved in the injustice of this situation that we were not going to let it go, even if we had to pay for it ourselves," she says. "We consider this an important thing to do. If we hadn't stayed involved, there never would have been this connection made to the Lariam problem in the military. The military has denied it up and down."

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For those suffering from Lariam side effects, knowing what's wrong is, at least, a huge comfort. Rogers thinks it may be the not knowing that's driven some people to suicide. "The not knowing just eats you up," he says in a deceptively breezy tone. Rogers has a low-key, offhand manner of speaking, common among military lifers that makes even the most emotional statements sound matter-of-fact. "You've got guys wandering around with some damage that aren't being taken care of. They're probably watching their family lives deteriorate. If they knew what the problem was, you could salvage some lives. But the military's not real quick to move on this one."

In fact, Rogers says there's a concerted effort to sweep Lariam problems under the rug. "The way the military's dealing with this is by not dealing with it. I was in a PTSD [post traumatic stress disorder] group meeting today and some people asked about Lariam and we were told by the group mentor that he had direction from a higher command that we weren't allowed to discuss this anti-malarial medication or hand out information in the group. So I asked him," Rogers continues with no change in inflection to betray the sarcasm of his words, "if it was OK if I brought my manuals on stand-off assassination techniques and we went over that stuff."

Word of the ban on Lariam discussion quickly got back to Steve Robinson at the National Gulf War Resource Center. "That's very troubling because it flies in the face of what PTSD counseling is all about," he says. "By inhibiting them and not answering their questions and not allowing them to discuss their concerns, they're inhibiting their recovery."

The military is also making it difficult for vets to get medical benefits. So even if a soldier figures out he's suffering Lariam side effects, he may not be able to get treatment. "The first question they're going to ask if you think Lariam hurt you is, show me in your service medical records where you took Lariam. And it's not going to be in there," says Robinson. "They're not tracking adverse events and they're not annotating it in people's medical records."

Robinson has seen this movie before: The military failed to record toxic exposures during the first Gulf War, and research scientists are still trying to solve the mystery of Gulf War illness. A former Airborne Ranger and Ranger Instructor, Robinson served with Special Forces in Iraq in

the 1991 war, then worked as an analyst for the DoD's Gulf War Illnesses research effort. He's been heading the National Gulf War Resource Center since 2001.

Robinson says that when the war in Iraq began, the military at first denied using Lariam on troops. "That story eventually changed over time, to where they admitted that some units had it, then lots of units had it, then most units had it." The question arose because a much less expensive anti-malarial, chloroquine, could have been used instead. Lariam, the brand name of mefloquine, was developed to be used in areas where the malaria carried by the local mosquitoes had become resistant to chloroquine. There is no such resistance in Iraq.

Chloroquine is not only cheaper, its side effects are fewer and considerably less severe. Considering what is known about mefloquine's contraindications, it's a wholly inappropriate drug to be giving combat troops. "The people that use this drug in war clearly fit a pattern of people that shouldn't take it," says Robinson. "It says right on the product insert, don't give to people who are depressed, who are in hypervigilant modes, people who need to have fine motor skills. Soldiers are scanning 360 degrees in a dangerous environment, having to make life or death decisions with their weapon."

Under pressure from the advocacy groups and adverse publicity, the Department of Defense ordered that Lariam be discontinued in Iraq. No such order was issued for Afghanistan, so it's assumed that troops there are still taking it. And Sue Rose suspects that they're still getting it in Iraq, too. "There's chaos over there. So I'm not at all sanguine that just because Washington says they're not using it that in fact it's not being used," she says. "We hear from troops in units whose commanders say they're not getting Lariam and they show us the pills, and that's exactly what they were taking."

DoD also announced that the Armed Forces Epidemiological Board will conduct a study of Lariam use among troops – although the lack of medical records will make such a study challenging at best. And in June, the Veterans Health Administration circulated a document to all VA clinicians describing possible side effects from the drug, with a summary of the findings from past research. The cover letter lists adverse effects "that are reported to persist for significant periods after the drug is stopped, or that could be associated with long-term health effects." These include depression, suicidal ideation, acute and paranoid psychosis and grand mal seizures.

Dr. Peter Jensen, chief of infectious diseases at the San Francisco VA Medical Center, remembers getting the notice. But when the section about long-term effects is read to him over the phone, he says, "I'd like to see the data on that because by and large drug effects don't cause irreparable damage. The effects of the drug for just about everybody clear when you stop the drug."

Bob Rogers has been back from Afghanistan since October 2002, and he's still running into walls and tripping over his own feet. His wife has filed for divorce because she doesn't know if she can ever feel safe with him again. Rogers hasn't given up hope that he can patch things up with her, but he can't guarantee that he'll never lose control again. "But I'm doing better," he

says. “A lot of times when you don’t know what something is, it’s very taxing. But once you understand what’s going on, it ain’t so bad. I can deal with it.”

Jeanne Lese says guys like Rogers shouldn’t have to be dealing with their ruined lives. “The frightening thing about this drug is that it affects those people that were so healthy,” she says. “Career service people in the prime of their lives, Special Forces who are in superb physical condition. And they take this drug and wind up with brain damage! This is a drug that takes healthy people and makes them sick.”

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Lariam Action USA can be accessed at www.lariaminfo.org. Send e-mail to info@lariaminfo.org.