

Don't Call It A Women's Disease — Men Get Lupus Too

By: Russell Wild

TV legend Charles Kuralt had lupus. So does baseball great Tim “Rock” Raines. And so do approximately 150,000 men in America today. Granted, that number represents only about one in 10 people with lupus, but it clearly belies the popular misconception that lupus is strictly a women’s disease.

“I certainly don’t fit the stereotype,” says Matthew Johnson, 27, a financial planner in Chesterton, Ind., who was diagnosed with lupus while still in high school. “Am I a woman of childbearing years? No. Am I black or Hispanic? No. Sometimes I just have to joke about it. What else can I do?”

No one knows for sure why lupus is so much more common in women or, for that matter, among people of color in the United States. “We know that hormones can regulate the severity of the disease, but we don’t know how hormones influence the incidence of the disease. Nor can we yet pinpoint the cause,” says Robert G. Lahita, M.D., chairman of medicine at northern New Jersey’s Liberty Health Hospital, Jersey City Medical Center Campus, and co-author of *Lupus Q&A: Everything You Need to Know*.

As for the severity of the disease, there is mystery here as well. “Some investigators say that lupus in men isn’t as bad as it is in women,” notes Lahita. “Others say it’s just as bad and maybe worse.”

Richard Hymowitz, M.D., a rheumatologist with Virtua Memorial Hospital in Mount Holly, N.J., agrees that although some lupus complications, such as pleurisy (lung problems), seem to be more common among men, the similarities in lupus between the two sexes far outweigh the differences. “Whatever differences exist are subtle ones,” he says. “The course of the disease is an individual thing. It doesn’t have all that much to do with gender.”

But the same cannot be said of how those with lupus react emotionally to their diagnosis—or how they cope psychologically with a chronic disease. In this regard, men with lupus by and large seem to handle their illness in a manner that’s distinctly manly.

Never Surrender

For Matthew Johnson, joking around about not fitting a certain stereotype is obviously easiest to do on days when he’s free of pain. But even on the other days, Johnson won’t let his lupus take control. “Some days my knees are so swollen, I feel like I can hardly get up. But I do,” he says. “I keep it in the back of my mind not to overexert myself, but I sure don’t stay in bed either. I play softball and volleyball and weight-train at the YMCA. I’m not going to let this thing defeat me.”

That never-surrender attitude is common among men with lupus. “I often have to chain these guys down,” Lahita notes. “I’ve got one man who jumps out of planes and another who scuba dives in remote corners of the world. I sometimes wonder if these men aren’t trying to overcompensate for having a so-called women’s disease by acting more masculine.”

Indeed, men with lupus tend not to get morose about their condition. “Men almost never give up trying to live a normal life,” says Lahita. “Most men I’ve known are real fighters.”

Don’t even try to talk to Zack Diersen about giving up. Diersen, 28, a marketing coordinator in Houston, Texas, was diagnosed with lupus five years ago. “It’s big, and it’s something you have to stay on top of. I take 10 pills a day—but, hey, as long as I do that, I should be okay. Lupus isn’t the end of the world,” says Diersen.

“I play golf, swim, bike, shoot baskets and work out,” he continues. “I try to remember to avoid heavy-impact things, like jogging, but other than that, I’ll do just about anything. I won’t let this thing get me down. I am determined to live a full, normal and happy life.”

Money, Power and Sex

But men, for all their apparent bravery, face certain special psychological challenges. Some men may fear no longer being able to perform sexually. In most cases of lupus, however, such fear is wholly unwarranted. “Most of the men I see with lupus have normal levels of testosterone and no loss of sperm,” says Lahita. “They are sexually potent and very virile.”

The only apparent connection between male sexuality and lupus is this: Older men who lose testosterone (a normal part of aging) may become more susceptible to autoimmune and autoimmune-like diseases, such as lupus. At the same time, that loss of testosterone may cause a loss of libido. But this has nothing to do with younger men.

Another fear among men with lupus is that they will no longer be able to provide for their families. Although society and the roles of men and women have changed, many men still feel that they are the ones who are supposed to bring home the bacon. Lupus—with its attendant muscle aches and joint problems—can make that difficult, especially for men whose work involves physical labor.

Richard Simko, 70, of Portage, Ind., was already the father of six when, in 1984, he was diagnosed with lupus after a number of erroneous diagnoses. He had to quit his job as a maintenance man with a steel company, and his family struggled to make ends meet.

“Men are men. They want to carry the load. Not being able to do that was very hard for Richard,” says his wife, Phyllis. But life for the Simkos went on. Disability insurance, Phyllis’s modest salary as a bookkeeper and a little money in the bank allowed the large family to squeeze by. They now have 16 grandchildren and one great-grandchild, and they recently celebrated their 50th wedding anniversary.

Staying Strong

Al Cohn of Lenexa, Kan., remembers that when he was first diagnosed in 1979, “everything seemed to go to hell.” But after eight initial months at the Mayo Clinic, Cohn survived two near-death experiences and 17 operations (he had cancer as well as lupus). Several decades on, Cohn, now 69, is proud to say: “I’m still kicking!”

To say the least. He spends 30 hours each week doing volunteer work and serving on the boards of two local charities and with the National Red Cross. “I’m working harder now than when I had a job,” says Cohn. It’s exactly this kind of indomitable, get-up-and-go spirit that leads some doctors to see men such as Cohn as model patients. “It’s an extraordinary group,” says Lahita. “These men have a wonderful attitude.”

But it is not only men with the disease who can inspire. Sometimes it can work the other way around. Matthew Johnson, for example, found plenty of motivation in a female branch of his family tree. “After I was diagnosed, I discovered that my great-grandmother on my father’s side had lupus,” he says. “She also raised 13 children and lived to the age of 83. Lupus didn’t get the better of her—and it won’t get the better of me.”

Russell Wild, a journalist in Allentown, Pa., writes about health and finance for AARP The Magazine, Men’s Journal and other publications.

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Sidebar:

Men Turning to Support Groups

Lupus support groups for men tend to be very different from those for women, says Suzanne Tierney, who has lupus and is executive director of the LFA’s Greater Cleveland chapter.

“Men tend not to open up and share the same way that women do,” explains Tierney. “They may get together and talk mostly about golf and football, occasionally exchanging a story and maybe throwing out a few ‘attaboy’s or ‘good job’s.” But although they often skirt the emotional issues, she says, “The men give each other the ego boost that any person with a chronic disease needs. And they walk away with a feeling of having bonded with men who are in the same boat.”

Rick Barbour, 60, of Columbus, Ohio, was diagnosed with lupus 22 years ago, but he didn’t attend his first lupus support group until relatively recently. “I bumped into an old school chum about four years ago, and I told her that I had lupus.” It turned out that the old friend has lupus too. “She invited me to her support group. I came, and I’ve kept coming,” he says. “I love it!”

The group is predominantly women, but that doesn’t bother Barbour a bit. “I find support and fellowship,” he says. “Not only do we talk, but we go swimming together, take cooking classes and occasionally go to the movies.” So enamored is he of the group that he’s now working to start a second support group—this one for men only—that he himself will facilitate.