

## Risk & reward: Stopping a cancer drug to see if you're cured

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In this Jan. 31, 2017 photo, Rick and Nina Schmidt sit at the table of their home in Hartland, Wis. Nina Schlidt was diagnosed with chronic myelogenous leukemia in 2009 and had to take drugs to control it for six years. After she went into remission, she qualified for a study led by the Medical College of Wisconsin, allowing her to go off treatment completely. Her husband had to delay retirement until age 70 so they would have insurance to pay for the drug. (AP Photo/Carrie Antlfinger)

Imagine you had a life-threatening cancer that a wonder drug had kept in

remission for years. Would you risk quitting?

Thousands of people with a blood cancer called [chronic myelogenous leukemia](#), or CML, now have that choice.

New treatment guidelines in the U.S. say certain [patients](#) can consider stopping Gleevec or similar drugs which were long thought to be needed for the rest of their lives. It's just a pill or two a day but the drugs are expensive and have side effects.

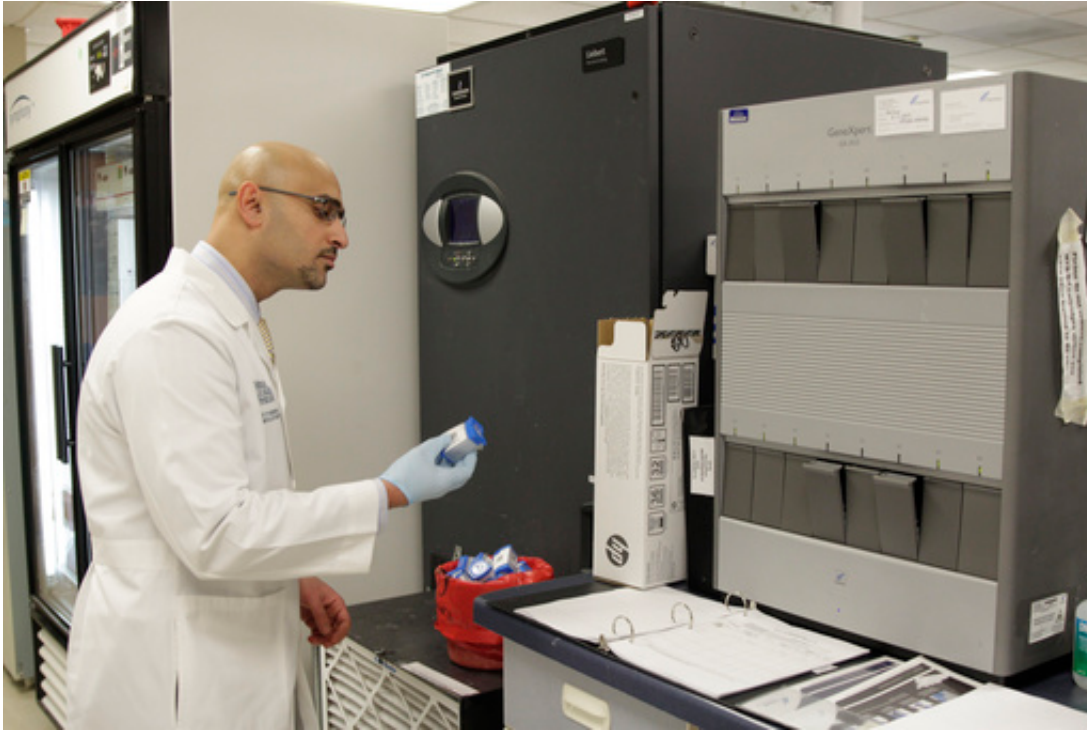
A European study recently found it's safe for carefully selected patients to try, and a U.S. study hoping to confirm that just finished enrollment.

"Our goal is to truly cure CML, which is essentially to have patients off drug," said Dr. Ehab Atallah, a leukemia expert at the Medical College of Wisconsin who helps lead the U.S. study. "We're hoping to figure out better who can and cannot stop."

Some patients want to try, but others won't dare.

"Like playing Russian roulette," said Jee-Won Schally, 54, a former history teacher from Milwaukee who has taken Gleevec for 10 years and doesn't want to stop.

Nor does Doug Jensen, 83, a retired engineer near Portland, Oregon, who still gets the drug for free because he was in the original study that proved it worked.



In this photo taken Feb. 10, 2017 at the Wisconsin Diagnostic Laboratories in Milwaukee, Dr. Ehab Atallah demonstrates a machine similar to one that tests blood samples in a study of chronic myelogenous leukemia, or CML. Atallah, a leukemia expert at the Medical College of Wisconsin, helps lead a U.S. study that is trying to determine which patients can safely stop taking drugs that control the disease. (AP Photo/Carrie Antlfinger)

But for Nina Schlidt, quitting a similar drug nearly two years ago was wonderful and "financially, a godsend." The 67-year-old suburban Milwaukee woman's husband delayed retiring until 70 to keep insurance to cover her drug, which would have cost her thousands.

Meghann Bell, 38, a marketing director in Seattle, went off Gleevec in 2010 to start a family because the drug isn't safe during pregnancy. She resumed after the birth, then decided to go off again two and a half years ago.

"I kept thinking how I had been in remission" during pregnancy, she said. "I felt like I was cured and really didn't want to be on this drug for all my life."

CML, which starts in the bone marrow, has long been unique. Some other types of cancer, such as breast or colon, are treated with surgery or a course of radiation or drugs and the tumor either is gone or not, and may or may not recur. But once CML develops, it has been considered a lifelong threat. It's almost always caused by a gene flaw that usually develops during life, versus one that is inherited.

Gleevec blocks the gene's activity in more than 90 percent of patients. The drug's approval in 2001 turned CML from a fatal disease to a chronic condition for most folks, and 36,000 to 100,000 Americans are living with it now, the Leukemia & Lymphoma Society estimates.

Two similar drugs, Tasigna and Sprycel, also are sold, and generic Gleevec came out last year. Treatment costs \$60,000 to \$150,000 a year. Even with insurance, copays run \$1,000 to \$24,000 a year, and Schally had to meet a \$10,000 deductible.



This photo taken Friday, Feb. 24, 2017 at the Froedtert & the Medical College of Wisconsin Clinical Cancer Center Pharmacy in Wauwatosa, Wisconsin shows the drug imatinib mesylate, also known as Gleevec, used to treat chronic myelogenous leukemia, or CML. The Medical College is leading lead a U.S. study that is trying to determine which patients can safely stop taking drugs that control the disease. (AP Photo/Carrie Antlfinger)

Side effects can include fatigue, nausea, chronic diarrhea, muscle pain and skin rashes. Meals have to be timed carefully around some pills. Many patients want to quit, but the thinking was that they would always need treatment, the way some people need insulin to control diabetes.

Now, though, research suggests that long treatment may eliminate so many cells with the bad gene that the immune system may be able to keep the disease in check if it starts to return.

At an American Society of Hematology meeting in December, Dr.

Francois-Xavier Mahon of the University of Bordeaux in France reported a study of 750 patients who stopped treatment after being in deep remission with no sign of disease in their blood for at least a year. After six months without treatment, 62 percent had maintained a deep remission, and 52 percent still had after two years. Most who relapsed were able to regain deep remission after resuming treatment, and none developed advanced disease, he said.

Half a dozen smaller studies have been done, and "the data are all the same and it all looks good," said Dr. Kendra Sweet of the Moffitt Cancer Center in Tampa. She helped draft new National Comprehensive Cancer Network guidelines that say it's reasonable to consider stopping treatment in people who have been in deep remission for at least two years, with close monitoring.

Not only some patients are wary, some doctors are too.

"If I can keep a patient on medicine, I do," said Dr. Mikkael Sekeres, the Cleveland Clinic's leukemia chief and a spokesman for the Hematology Society. "There are those of us who don't think you can cure the disease with long-term treatment," that eventually it will come back.



In this photo taken Friday, Feb. 24, 2017, in Wauwatosa, Wisconsin the drug Sprycel sits on a shelf at the Froedtert & the Medical College of Wisconsin Clinical Cancer Center Pharmacy. It's a drug used to treat chronic myelogenous leukemia, or CML. The Medical College is leading lead a U.S. study that is trying to determine which patients can safely stop taking drugs that control the disease. (AP Photo/Carrie Antlfinger)

But Gleevec's discoverer, Dr. Brian Druker, head of Oregon Health & Science University's [cancer center](#), sees it differently. Nearly half of his 250 patients would be eligible to try quitting. So far, 49 have and only 18 have had to resume.

"When I discuss it with patients, I say there's a 50-50 chance you'll be off therapy and a 1 percent risk that your leukemia will become resistant to [treatment](#)," Druker said. "Those are pretty good odds."

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