

From Lung Cancer Patient to Patient Advocate

Janet Freeman-Daily's journey highlights how advances in lung cancer testing and treatment can save lives.

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A clinical trial at the [University of Colorado Cancer Center](#) in 2012 saved Janet Freeman-Daily's life in more ways than one.

Now living with no evidence of active [lung cancer](#) for more than a decade, thanks to a capsule she takes once a day, Freeman-Daily has also found a new sense of purpose as a full-time patient advocate.

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— CU Cancer Center ([@cucancercenter.bsky.social](#)) [June 23, 2025 at 1:04 PM](#)

"I started out by speaking about patient involvement, and now I help run the International Association for the Study of Lung Cancer's STARS [Supportive Training for Advocates on Research and Science] Program that trains patient research advocates," she says. "I also help run The ROS1ders [pronounced 'ross wonders'], which is a global group of patients and caregivers living with ROS1-positive cancer."

Freeman-Daily was diagnosed with lung cancer in 2011 but did not know she had a very specific subtype called ROS1-positive lung cancer until a year later. She now works to make other patients

aware of the cancer subtype and the importance of staying involved in your own care.

“It’s extremely important to advocate for yourself,” she says. “In the case of ROS1, which is driven by an acquired fusion in the ROS1 gene, most of the doctors we encounter will have never met a person with this type of cancer.”

A new lung cancer diagnosis

Before she was found to have the rare genetic fusion, Freeman-Daily was a newly diagnosed lung cancer patient trying to make sense of what was happening to her body. She first noticed symptoms after a family trip to China in 2011.

“Everybody got an upper respiratory infection from being on the plane,” she says. “My husband and son cleared in about a week, but I started coughing up green gunk and blood. The doctor gave me two different rounds of antibiotics, neither of which did anything, then they did an X-ray and a CT scan. Just as I got home from the appointment, they called and said, ‘We think you’ve got lung cancer.’”

The tumor was deemed inoperable because of where it was located in Freeman-Daily’s chest, but she began a course of chemotherapy and radiation, which shrank her tumor by 90%. Follow-up scans, however, revealed the cancer had spread to nearby lymph nodes, as well as her neck. When the cancer showed up in her other lung, she knew she had to explore other treatment options.

“I was part of an online lung cancer group where I learned about ROS1 from other patients, but I couldn’t find a way to get tested,” says Freeman-Daily, a former aerospace systems engineer who now lives outside of Seattle. “My doctor said I was probably going to have to be on chemo for the rest of my life.”

A fateful trip to the Mile High City

Freeman-Daily’s luck changed when she and her husband went to visit a nephew who lived in Denver. Freeman-Daily had briefly been part of a CU Cancer Center-led effort to screen lung cancer patients for multiple mutations, and she had tested negative for all of them. But as long as she was in Denver, she thought, she might as well try to connect with the head of that project — [Paul Bunn](#), MD, the first director of the CU Cancer Center — to see if there was any additional help he could offer.

“I reached out to the person who coordinated my testing at the CU molecular correlates lab, and she said that Dr. Bunn would be willing to meet with me the next day,” she says. “So I went to the lobby of the Anschutz Cancer Pavilion, and he came down in his white lab coat on his lunch break, and he told me they had two new tests. I said, ‘Is one of them to test for ROS1?’ And he said, ‘Yes.’”

Bunn's group still had some of Freeman-Daily's tissue from the first trial, so he tested it for ROS1 and found the cells to be "wildly positive" for the genetic fusion. Not only that, but he knew of one spot left in a clinical trial for a new drug to treat ROS1-positive lung cancer.

"I was diagnosed in 2011, and ROS1 was only discovered in January of 2012," Freeman-Daily says. "They found that it tended to be detected in people who were younger, never smokers, and negative for the two known lung cancer mutations. I fit all those checkmarks."

Freeman-Daily began taking the new drug capsules directed against ROS1 as part of the clinical trial, and when she returned for her first follow-up appointment eight weeks later, her scans showed no evidence of the disease.

"It was amazing," she says. "I was texting everybody with the news."

[Ross Camidge](#), MD, PhD, the CU Cancer Center member who was the principal investigator on the ROS1 trial, says Freeman-Daily's case goes to show that the right drug, in the right patient, can have remarkable results.

"Janet is a great example of the fact that, if you find the right drug, just occasionally, your cancer can have real trouble finding a way around it," says Camidge, the Joyce Zeff Endowed Chair in Lung Cancer Research. "The best scenario is to have a very dumb cancer that can't figure its way past whatever block you put in its way."

A patient advocate is born

Freeman-Daily still takes the medication, which is now FDA-approved for treatment of ROS1-positive lung cancer, and she sees a local oncologist in Seattle every six months to make sure the cancer hasn't made a return. She remains connected to the CU Cancer Center as a member of the executive committee of the [Thoracic Oncology Research Initiative](#), and she has enlisted Camidge to help with her advocacy efforts.

"Dr. Camidge was wonderful," she says. "He always answered all my questions, and he always had a plan for next steps, should something go wrong. We talked about the new research — being a science geek, I liked that. I started sharing my advocacy work with him, and now he's on our Scientific Advisory Board for The ROS1ders."

For his part, Camidge says he is gratified to have led the trial that made such a difference for Freeman-Daily, whom he now considers a friend and a colleague, as well as a former patient.

"As a clinician, you want the cancer to be a footnote in somebody's life, not the headline," says Camidge, who continues to do research into the ROS1 fusion and why patients like Freeman-Daily have such a positive response to the medication while others do not. "She chose to use the time she had to give back, to help others. She has become an elder statesperson of patient advocacy."

That patient advocacy work, which she started soon after enrolling in the clinical trial, comes naturally to her, Freeman-Daily says.

“I felt really grateful, and I wanted to give back,” she says. “I like writing and research, so I started out blogging and educating other patients using my science background. It evolved from there.”

She’s “probably saved some lives,” Freeman-Daily says, by helping people get the right treatment or directing them to second opinions. “It feels good to know you’re making a difference for other people,” she says.

“It’s like I found my purpose,” she adds. “I have my writing and speaking skills, and my engineering analysis skills and my interest in science, and I get to use all those things on a daily basis, doing things that make a difference for other people. I have to wonder if having that purpose isn’t part of the reason I’m still here.”

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