

Clinical trials helped one woman's fight against cancer

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Monica Barlow

And new tool for finding the right match may help others get novel treatments.

(HealthDay)—Monica Barlow, a 35-year-old from Maryland, was training for a half-marathon when she noticed she couldn't shake a bad cough and ongoing fatigue. After a couple of rounds of antibiotics from an urgent care clinic didn't work, she sought another opinion.

A [CT scan](#) brought wrenching news: There was a tumor in her left lung.

"I never smoked, I eat well, exercise and had never had any medical problems prior to this," Barlow said. "To say it was a shock doesn't even begin to describe it."

Four years later, Barlow has been through a series of ups and downs.

After learning the cancer had spread to her [lymph nodes](#) and liver, she started chemotherapy, which only shrunk the tumors temporarily. She then joined two consecutive clinical trials, each offering to help control her cancer with [novel drugs](#).

Barlow, who is director of public relations for the Baltimore Orioles baseball team, credits her participation in those clinical trials with prolonging her life.

Clinical trials test potentially promising treatments for a wide range of challenging diseases. But it can be difficult to find a good match for your particular situation and tough to know where to start looking. Even when you join a suitable trial, the outcomes are far from a sure thing.

Such has been the case for Barlow.

After she found out the lung cancer had spread to her lymph nodes and liver, she started an 18-week course of intravenous chemotherapy—[carboplatin](#), [pemetrexed](#) (Alimta) and [bevacizumab](#) ([Avastin](#)). Then there was some good news: The treatment had stabilized or shrunk all of the tumors.

A year later, her doctor found that the [liver tumors](#) were back. Because he discovered Barlow carried the ALK [gene mutation](#), he suggested she join a clinical trial for a medication called crizotinib (Xalkori).

Initially, she didn't know if she was taking the real drug or a placebo. "That was a concern," she said. "It wasn't great to hear; it was stressful." Later in the trial, all patients were able to get the actual drug and placebos were no longer given to anyone, she said.

Barlow took Xalkori for two years, but last year the cancer returned yet again, requiring three ablations (localized methods to destroy a tumor

without removing it) and two chemoembolizations (which deliver chemotherapy directly to the liver tumor while minimizing exposure to healthy tissues). Those procedures were not effective, and the next step was surgery to remove almost half of her liver.

Then, when tumor growth appeared in the new liver tissue that had grown back after the surgery, her doctors suggested she try a second clinical trial for a drug called LDK 378, which is being developed by Novartis.

The treatment continues to be tough. "This drug is a lot more difficult for me to take [than the drugs in the first clinical trial]," she said. "There are a lot of side effects, like nausea and vomiting."

Although the medication seems to be shrinking her liver tumors, just recently she had problems with a lung infection and a collapsed lung after a bronchoscopy. That has forced her to take a break from the trial; she hopes to restart as soon as the infection is gone.

Barlow continues to work, traveling with the team when she can. When she's sidelined by her illness, she's frustrated. "I can't believe I had to miss opening day [for the Orioles] this year," she said.

Because she has what she calls "excellent insurance," Barlow hasn't had to face serious medical bills. There is no charge for the care associated with her clinical trial, she said. But she and her family pay for the cost of traveling to her clinical trial site in Philadelphia, including hotel and meals, which can add up when she has an occasional hospital stay there, she added.

The drug Barlow is taking now wasn't available when she was diagnosed three years ago, she said.

"There are so many new things coming out, changing how cancer is being treated, so it's really important to be your own advocate or have someone who is advocating for you," she said. "The Internet can be a huge way to help you stay on top of the latest resources."

Barlow's fight highlights the potential value of a new system to help people more easily access clinical trials, both near and far from home.

A new Internet resource, MyClinicalTrialLocator.com, has just been launched to make it easier for people to find clinical trials that fit their needs.

Dr. Bruce Moskowitz, an internist in West Palm Beach, Fla., gave \$100,000 from the Bruce and Marsha Moskowitz Foundation to help support the development of the free website.

"We made this site to be easy to use and understandable to anybody: patient-centric, not doctor-centric," Moskowitz said. "Hopefully, anyone will be able to receive help if they need it."

The website is designed to help visitors search for trials available by medical condition, treatment, location, medical center or other terms. It's accurate, updated frequently and includes information from clinicaltrials.gov (sponsored by the U.S. National Institutes of Health) and academic medical centers, Moskowitz said.

The site offers information about clinical trials worldwide, provides a mapping function to pinpoint the location of a trial and will notify users when trials matching their needs become available. It also allows patients to email clinical trial researchers directly, and academic medical centers can update and correct information on the site in real time.

Despite her many challenges, Barlow thinks [clinical trials](#) will help

extend her life. "I know this drug won't work forever. But there will be other drugs out there, drugs [that are now] in the early stage of development, and when I need them, I'll switch to those drugs," she said. "The answers are out there; it's just a matter of researchers finding them."

More information: Visit the U.S. National Library of Medicine to learn more about [clinical trials](#).

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