

Targeting Rare Cancers for Research and Treatment

Even the top doctors know little about some of these diseases. A nonprofit is focused on changing this situation.

by Jonathan Friedman
Editor

When Dave Webster, a healthy and active 47-year-old man, began feeling ill in 2011, it took him and his family by surprise. Doctors thought he possibly had gallstones, and tests were done. When they looked for the gallstones, they instead found a blockage and discovered he had an extremely rare form of cancer affecting the bile duct called cholangiocarcinoma. There was no known treatment for the disease, and even the top doctors did not have much knowledge of it at all.

Webster's wife Joann said the news of the diagnosis rocked the family's world because they had no idea why he had the disease and how he could be helped. It was especially confusing for the couple's children Amanda, David and Katie, who had seen their mother defeat breast cancer twice.

"When my kids saw me with breast cancer, I was fine," she said. "I did treatment and I was OK. So of course, they thought

that their father's condition was going to be the same. But it's not the same because they don't have the treatments for this. There needs to be more research."

Dave Webster received his diagnosis in May. For the remainder of his life, he was treated with what was no more than palliative care, and he was "miserable every day," Joann Webster said. He died in December.

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—Joann Webster

During Webster's final months of life, his wife, who is a registered nurse, tried to learn as much about this rare disease as she could. In her research, she discovered the Cambridge-based nonprofit TargetCancer that was founded in 2009 by Paul Poth, an attorney who had been diagnosed with cholangiocarcinoma at age 38 despite being a healthy and active man. He was frustrated how even the world's top oncologists had little

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Dave Webster died from cholangiocarcinoma in 2011 at age 47. He was a healthy man before the diagnosis.
Photo courtesy of Joann Webster



Paul Poth stands with his wife Kristen. He died in 2009 from cholangiocarcinoma and founded TargetCancer.
Photo courtesy of TargetCancer



TargetCancer volunteers and staff attend Founder's Day in Saugus to promote awareness of the nonprofit and tell people about the June 14 fundraiser. From left: Sandy Reid, David Webster, Joann Webster, Jim Palma and Bob Davis.
Photo by Jonathan Friedman



Photo courtesy of Jason Freedman



Participants in the Dave Webster/TargetCancer Community for a Cure event launch balloons into the air at World Series Park.
Photo courtesy of Jason Freedman

Funding Research

In its short existence, TargetCancer has raised more than \$250,000 to fund research of rare cancers.

Making an impact through targeted grants

The organization has only been around for a short time, but TargetCancer already has some accomplishments on its resume. It has raised more than \$250,000 to issue grants that go toward research on rare and lesser-known forms of cancer, including cholangiocarcinoma. The grants include:

- **\$120,000 to support** cholangiocarcinoma research at a laboratory at the Massachusetts General Hospital Cancer Center
- **\$62,000 to create** and fund the ongoing operations of the TargetCancer Cholangiocarcinoma Cell Line Bank at Massachusetts General Hospital
- **\$45,000 to a** laboratory at the Dana-Farber Cancer Institute to support esophageal cancer research; results were recently published in Nature Genetics
- **\$25,000 over three** years to establish the TargetCancer Medical Student Research Fund at Harvard Medical School
- **\$7,500 to the** Center for Molecular Therapeutics at Massachusetts General Hospital Cancer Center; this was the original grant made by TargetCancer founder Paul Poth

—**Jonathan Friedman, information obtained from TargetCancer documents**

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knowledge of the disease. She and her family connected with TargetCancer, and have been working with the organization to fund research that could lead to treatment of the disease.

Poth lived with cholangiocarcinoma for nearly two years until he died from the disease. This gave him more post-diagnosis months of life than most other people with cholangiocarcinoma have had. He used this extra time wisely to care for his wife Kristen and young son Luca, but also to found TargetCancer, which has a mission of funding research of not just cholangio-

carcinoma, but also other rare and lesser-known cancers.

“He was a healthy young person and they couldn’t do anything for him,” said Jim Palma, Poth’s brother-in-law and TargetCancer’s executive director. “It was crazy in 2009 that this would be happening. He started raising money and gave a grant while he was still alive. My sister made the decision to keep the foundation going and it went on from there.”

Poth said in 2009, “The fact is that I have heard oncologists and nurses comment that almost too much is known about certain cancers whereas others simply languish. Researchers are working on the lesser cancers, but they need help. I want to spearhead that help.”

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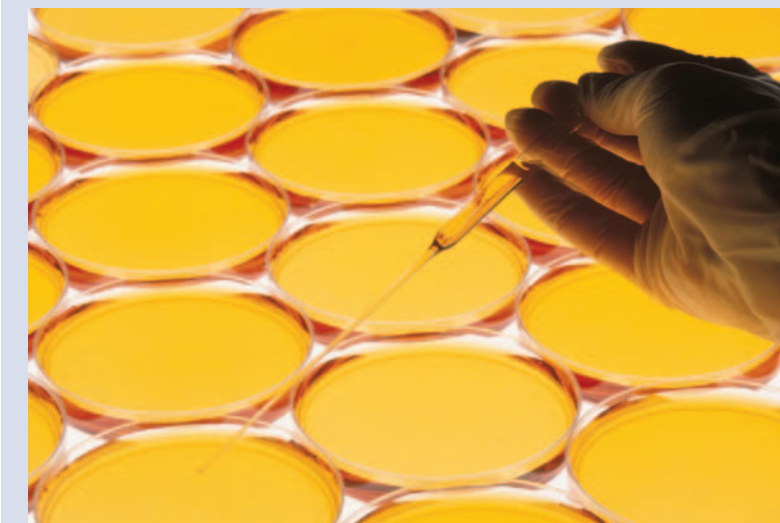
—Paul Poth

TargetCancer has raised more than \$250,000, including

more than \$27,000 from the Dave Webster/TargetCancer Community for a Cure event in September that included supporters walking in Saugus from the First Congregational Church to World Series Park. More than 500 people participated. The money raised at the event is being used to fund the second year of a program at Massachusetts General Hospital to create a cholangiocarcinoma cell line bank. The formation of these cell lines allow doctors to do research on the disease.

“With more common cancers, this is the research that was done a real long time ago,” Palma said. “We’re doing the basic research now that’s going to lead to the treatments for people with this. So, there aren’t treatments today, but we’re really encouraged by what we’re seeing, and there is the possibility of having clinical trials very soon.”

A second edition of the Saugus fundraiser will take place June 14 at World Series Park. It will include a walk and entertainment. More information about the event will be available soon at targetcancer.info. The website also contains extensive information about the nonprofit, including its accomplishments and how people can support it toward its goals.



TargetCancer is raising money to issue grants that fund medical research that could lead to the development of treatments for rare and lesser-known cancers.

Photo courtesy of hibu

TargetCancer's Founding Year

2009

Paul Poth founded the nonprofit after he was diagnosed with a rare form of cancer for which there is no treatment.