

FIRST OPINION

## My daughter is gone but her legacy lives on through her writing and phage therapy

By Diane Shader Smith Nov. 13, 2019

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Mallory Smith at her desk writing the book "The Gottlieb Native Garden: A California Love Story"

JACOB JONAS

“Who lives, who dies, who tells your story?”

That line from the musical “Hamilton” inspires me to keep telling the story of my daughter Mallory. She died two years ago Friday at the age of 25, two months after receiving a transplant to replace both of her lungs, which had been ravaged by cystic fibrosis and an infection that no drugs could eradicate.

Mallory was a prolific and gifted writer. In addition to works published as a journalist and [environmental storyteller](#), she kept a private journal for 10 years. She gave me access to it right before her transplant — in case she didn’t “make it to the other side,” she told me. With the help of other family members, Mallory’s friends, and wonderful editors, I collected some of her diary entries into a book, [“Salt in My Soul: An Unfinished Life,”](#) that Random House published this spring.

Mallory used to say that writing healed her. I wish she could know that her writing is healing others, something I have seen in nearly 100 talks I have given to medical students and physicians, nursing students and nurses, and therapists and researchers of all kinds about my daughter’s insights into invisible illness, insurance obstacles, the need for balance with pain medications, access to health care, and health care itself.

Mallory is also helping heal people whose lives are threatened by once-untreatable infections, which is what ultimately ended her life.



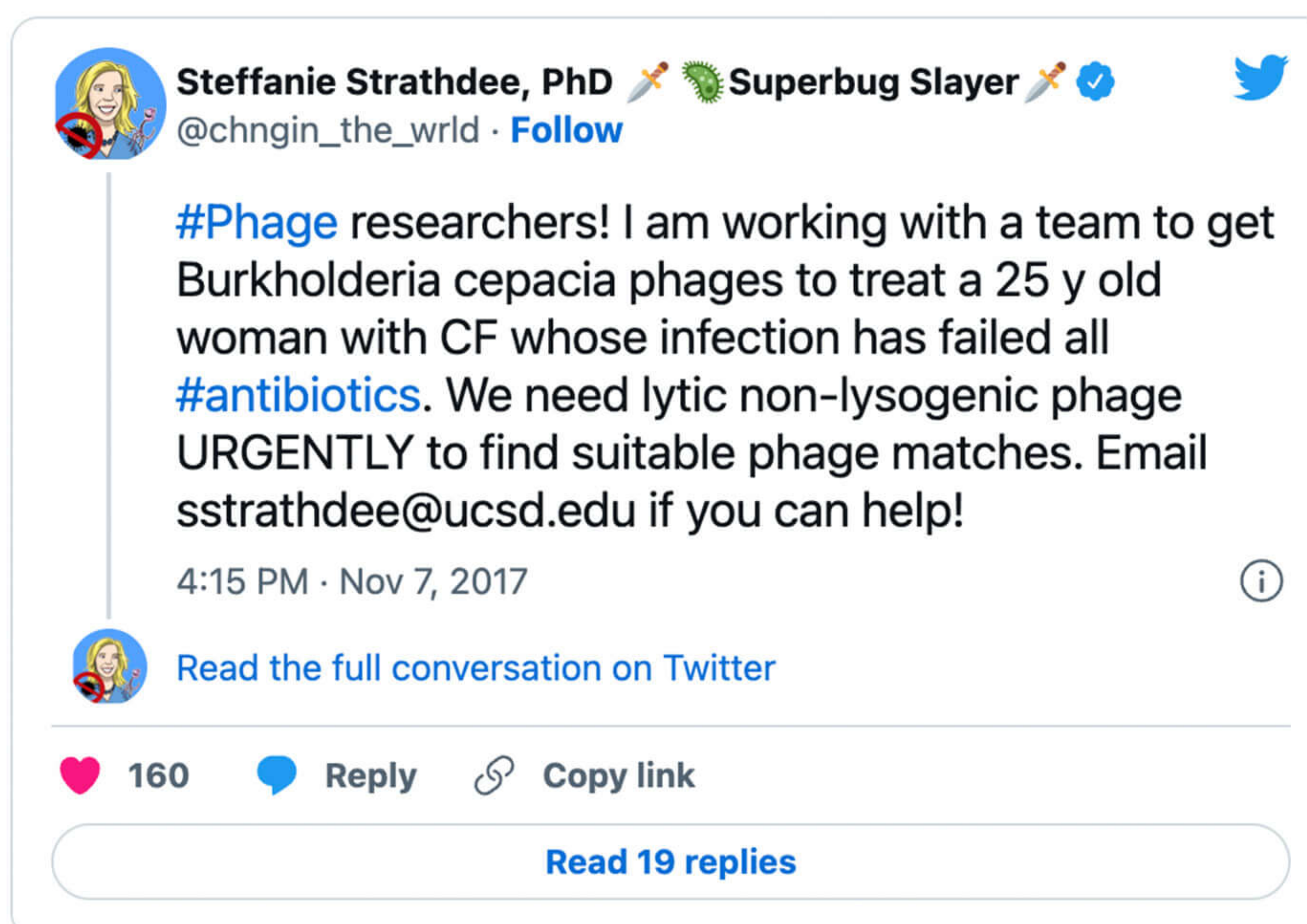
Here's the back story:

Mallory was diagnosed with cystic fibrosis when she was three. At age 12, a type of bacteria known as *Burkholderia cepacia* invaded her lungs. She didn't let any of that stop her from becoming a three-sport varsity athlete in high school or a club volleyball player at Stanford, where she graduated Phi Beta Kappa.

During Mallory's sophomore year in college, her lungs started to deteriorate. She needed a lung transplant, but wasn't a good candidate for the procedure because of the *Burkholderia*. After a long wait — and stall tactics by our insurance company — the University of Pittsburgh Medical Center accepted Mallory into its transplant program. It was the only center in the country that performed transplants on individuals with cystic fibrosis and *Burkholderia* infections.

Mallory got her new lungs on Sept. 11, 2017, and was soon walking and doing physical therapy. The bacteria, though, emerged from their hiding places in her upper airway and sinuses and once again colonized her lungs. Because the bacteria were resistant to antibiotics, her dad, Mark Smith, resurrected an idea he had only partly pursued earlier: an experimental approach called phage therapy that uses a type of virus known as a bacteriophage — which means bacteria eater — to attack the *Burkholderia* running amok in Mallory's new lungs.

In desperation, Mark reached out to Steffanie Strathdee, an epidemiologist at the University of California San Diego who had once saved her husband with phage therapy. [Strathdee's tweet](#) on Nov. 7, 2017, galvanized the far-flung community of phage researchers.



Within a few days, scientists at Adaptive Phage Therapeutics, a biotech startup in Maryland, in collaboration with the U.S. Naval Medical Research Center, found a bacteriophage they believed would attack the strain of *Burkholderia* in Mallory's lungs.



But time was running out. Mallory's transplant surgeon, Dr. Jonathan D'Cunha, arranged for the University of Pittsburgh's organ harvesting plane to pick up a container of the bacteriophage in Maryland and fly it to Pittsburgh, and then a helicopter to bring it to the hospital.

Mallory received the first dose of the phage cocktail on Nov. 14, but it was too late. Dr. Joseph Pilewski, co-director of UPMC's cystic fibrosis program and Mallory's beloved doctor, told us that she had suffered irreversible brain damage from the infection. She died the next day.

An autopsy later showed that the phage therapy had been working: the bacteriophages had reached their targets and were doing what they were supposed to do.

Mark couldn't save his daughter, but he was determined to save others with cystic fibrosis. He [turned to the media](#), established Mallory's Legacy Fund at the Cystic Fibrosis Foundation, and then spoke with Dr. Michael Boyle, the foundation's senior vice president of therapeutics development, to share his vision: Mark wanted kids with cystic fibrosis to get phage therapy before infections destroyed their lungs.

Boyle was incredibly receptive and asked for an introduction to Strathdee and Dr. Robert Schooley, co-directors of the [Center for Innovative Phage Applications and Therapeutics](#) at the University of California, San Diego. Mark and I raised \$100,000 and made an inaugural grant to the center to fund the first clinical trial of phage therapy.

My tour promoting Mallory's book has let me share Mallory's insights and Mark's dream with audiences at Harvard, Stanford, the University of Pennsylvania, and many other medical institutions. A trio of Australian researchers published [a review of phage therapy](#) in the journal *Frontiers in Cellular and Infection Microbiology* highlighting the work being done in this long-neglected field. Our phones started ringing, emails were flying — people wanted this treatment.

We introduced desperate patients and family members to Strathdee and Schooley. After I gave a talk at the University of Virginia School of Law, Mark spoke about the successful application of phage therapy in a [patient in the United Kingdom](#) with a drug-resistant infection. He also mentioned a patient with cystic fibrosis who had initially been denied a place on the transplant list but was later included after [receiving phage therapy at Yale](#). A young woman in the audience introduced herself to Mark, saying, "I'm Ella Balasa, the Yale patient." Ella connected us to the Yale team — pulmonologist Jon Koff and biologist Ben Chan.

A few days later, Mark met with Koff and Chan, participated in environmental phage collection and recorded footage of a patient receiving phage therapy. It kept going from there.



Two researchers inspired by Mallory's case, Jessica Sacher and Jan Zheng, have created [Phage Directory](#), the first phage therapy data bank.

Last week, [Israeli researchers](#) working on phage therapy told me they had found a match for the Burkholderia strain that infected my daughter. It was devastating for me to hear that, but it's another instance of her continuing to help and heal others. The researchers asked if they could name this phage prep after Mallory.

The resurrection of phage therapy couldn't be more timely. Many strains of bacteria, fungi, and other pathogens have become resistant to the antimicrobial drugs that once made treating infections a simple and routine part of medicine. The Centers for Disease Control and Prevention estimate that more than 2 million Americans are infected with antibiotic-resistant bacteria known as superbugs each year and as many as [23,000 die from these infections](#).

Although phage therapy still has a long way to go before it becomes part of mainstream medicine, Mark and I are confident it will get there.

Mallory wrote in her journal, "I feel like people with CF are privy to secrets it takes most other people a lifetime to understand ... How lucky we are to be alive ... That we can leave behind a legacy when we go that will impact others."

She has done just that. Rest in peace, Mallory, and keep inspiring others.

*Diane Shader Smith is a writer and publicist, cystic fibrosis fundraiser, and proud mother of Mallory and Micah Smith.*