

The community of science

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It was the very early morning of June 8, 2010, and I was standing in my pajamas between my two new bosses, Zak Kohane and Ken Mandl. I stepped through the doorway into the hospital room in front of us, where my husband lay, but Zak could not follow. In Orthodox Judaism, those from the kohen, or priest, line may not come into contact with the dead.

They had known Marco, my husband, longer than I had. In fact, Zak had recruited him to the Boston Children's Hospital Informatics Program (CHIP). In the months after the completion of the Human Genome Project, bioinformatics was generating a lot of buzz, so I attended a lecture Marco was giving. It was nothing like the talks I had seen before: in addition to explaining some of the mysteries of bioinformatics, it was entertaining. He kept the audience laughing and somehow interwove the Palio di Siena, a horserace in Siena, Italy. At the end, the chair of my department leaned over and said, "We've got to get to know this guy better."

In the days before he died, Marco was paying special attention to a new talk. He had been selected to get an award from Cremona, Italy, the city where he grew up and where we had been married. Cremona has a longstanding music culture. Stradivarius made his famous violins there. As a nod to that, he had titled his talk *La Forza del Destino* ('The Force of Destiny'), an opera by Verdi. Despite being an analytical, rational person, Marco was superstitious. He had warned me that *La Forza* was a cursed opera.

On June 8, we were supposed to have been on a flight to Milan. We went nearly everywhere together, having spent only three days apart in the three years we had been married. When he was admitted to the hospital on June 7 with chest pain and in heart failure, I stayed with him. They were going to run tests in the morning. Marco did not make it through the night.



Credit: US Department of Veterans Affairs

Other than a slight excess of black in my wardrobe, I am otherwise nothing like the stereotype I used to have of a widow. I am happy, and I am grateful for so much, including the enormous privilege of leading research and development at the Department of Veterans Affairs (VA). I certainly did not get here from that night in 2010 through some superior force of will. I leaned on every single one of the many people who offered to help.

The first were Zak and Ken, who rushed over when I called them in the middle of the night. I was no longer alone in that hospital. Zak had come with instructions from Heidi, his wonderful wife. He was to take me to their house. I was just days into my new job as executive director of the Substitutable Medical Applications, Reusable Technologies (SMART) project, for which

he and Ken were the principal investigators. I was supposed to be starting up the project. Instead, I was sleeping in the guest room in my new boss's house.

Throughout all of this, I wanted to work. I teleworked from my friends' homes in California and Florida, I cried at our first few executive committee meetings, and ultimately I worked with the entire SMART team to make a really satisfying contribution to health information technology.

After SMART, I went on to be executive director and co-principal investigator with Zak of the Undiagnosed Diseases Network Coordinating Center, which is doing astounding work to find answers for people with mysterious medical conditions. Then, in 2017, I joined VA, where we are embarking a transition to the Cerner electronic health record system, which runs third-party applications using the SMART technology we developed and Fast Health Interoperability Resource (FHIR, pronounced 'fire'), a healthcare data standard. I get a kick every time someone mentions 'SMART on FHIR', a shorthand I came up with one evening.

Just a couple of months ago, CHIP, where Marco worked, celebrated its 25th anniversary. Both Zak and Ken took time out of their speeches to remember him. One day later, Marco's former graduate student gave his firstborn the middle name Marco. This reminded me that although we researchers compete for funding and worry about others 'scooping' us, we are, at our best, a real community. I am so lucky to be a part of it. □

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