

## TANIA SIMONCELLI: Gene patent foe

*A US science-policy expert fought to keep genes open to all.*

**By Heidi Ledford**



Eero Simoncelli

In 2005, Tania Simoncelli managed to shock the senior lawyer at the American Civil Liberties Union (ACLU). Simoncelli, the organization's first science adviser, informed him that companies were snatching up patents on many human genes. "That's ridiculous!" exclaimed the counsel, Chris Hansen. "Who can we sue?"

It would not be that easy. Although the ACLU, a non-profit organization based in New York City, has spent nearly a century suing state and federal agencies for infringing civil rights, it had never challenged a patent. And the prospect seemed daunting in this case: the US Patent and Trademark Office had been issuing patents on human genes for nearly 30 years. But Simoncelli saw the practice as a threat to the right of individuals to access their own medical information, as well as to scientists' ability to do research on the genes.

Over the next four years, Simoncelli helped ACLU's lawyers to pull together a case and identify a suitable target for a suit — Myriad Genetics, a firm based in Salt Lake City, Utah, that had been particularly aggressive in defending its patents on two genes that

have been linked to breast cancer. And she rallied a consortium of scientists, patients and physicians to support the suit.

“She’s so persuasive,” says Hansen. “She’s persistent in a way that you don’t notice, until suddenly you’ve agreed with her.” Ultimately, the ACLU pursued the lawsuit to the US Supreme Court and, this June, won.

For Simoncelli, the experience offered the kind of interdisciplinary work that she had dreamed of doing since her undergraduate days studying biology and society at Cornell University in Ithaca, New York. “I wanted to be the person who could help bridge the cultures of science and justice,” she says.

After Cornell, Simoncelli earned a master’s degree in energy and resources from the University of California, Berkeley, then went to work at the ACLU in 2003. Her intention was to stay only two years before leaving to get her PhD in science, technology and society. She stayed for nearly seven — sometimes returning even after she left for the US Food and Drug Administration (FDA) in 2010, using her holiday time to continue work on the lawsuit.

Skipping that PhD was a difficult decision, recalls Sheila Jasanoff, a specialist in science and technology studies at Harvard University in Cambridge, Massachusetts, who taught Simoncelli as an undergraduate and has mentored her ever since. She suspects that Simoncelli has lost out on jobs and at times struggled for respect because she lacks the degree. But at the ACLU she was given the freedom to make her mark. “It was a place where her passion and drive didn’t get held back,” says Jasanoff.

At the FDA, Simoncelli has focused on policy areas such as nutrition and personalized medicine. She is currently working at the White House Office of Science and Technology Policy on forensic science — a project that brings her back to the intersection of science and justice.

“I’m really looking forward to seeing what’s next for Tania,” says Jasanoff. “She always surpasses my imagination.”