

From patient to patient advocate: how a cancer diagnosis fueled a new career path ^[1]

Discovery ^[2]

Almost 30 years ago, Elyse Spatz Caplan's oldest son hopped on a bus to go to summer camp while she drove to the hospital for surgery. A young mom of 3 boys under the age of 8, she had recently been diagnosed with breast cancer and was dealing with feelings of unease and uncertainty about the future.

While at Albert Einstein Medical Center in Philadelphia, Pennsylvania, Spatz Caplan received the best care offered at that time. When she was diagnosed, she set a goal to see her youngest start preschool. She set more personal goals throughout the course of her treatment, and they grew as she neared the end of her regimen. Still, those feelings of uncertainty were never far from her mind. At the time, patient support programs were limited, so she was inspired to do something constructive to help others. "With a cancer diagnosis, there's always uncertainty and fear," she says. "My antidote to that was to do something constructive to help people with cancer."

Pursuing a new career

As Spatz Caplan recovered from surgery and subsequent chemotherapy, she approached her oncologist with an idea. "With my academic training in speech pathology [and] psychology, and a teacher's certification, I thought if I paired my professional credentials with my experiences as a patient and caregiver, I might be able to contribute something meaningful."

The cancer center agreed, and ultimately created a new position for her: psychosocial program coordinator. In this pioneering role, Spatz Caplan would focus on helping address the needs of the whole patient – not just the patient's cancer.



Spatz Caplan (right) with her 3 sons and daughter-in-law celebrating love.

After 7 years at Einstein Medical Center, Spatz Caplan took on a new challenge when she decided to move from a medical institution to a nonprofit. During this period, big things were happening in cancer research; pathways responsible for tumor growth were being identified and researchers were hard at work developing treatments that targeted those pathways.

The changing landscape of both treatment and patient care continued to motivate Spatz Caplan, and she joined Living Beyond Breast Cancer (LBBC) as an education and outreach coordinator. Over time, she became the director of programs and partnerships, using her experiences as a patient and working with the organization to infuse the patient voice into their work.

Making a move to Novartis

Spatz Caplan spent nearly 14 years with LBBC, and again felt compelled to do more. At this point, more targeted treatments were being studied and developed, patients were becoming more informed and involved in their own treatment decisions, and patients were also beginning to expect more from the companies that provided their treatments.

She says she was drawn to Novartis because of its legacy in oncology. “The extent of cancer in my own immediate family – let alone my extended family – makes this very personal,” she says. “This is what gets me out the door every day. I’m very proud to work for Novartis because we have a strong focus in oncology, and most especially in breast cancer. That’s what drew me here.”

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As Director, US Patient Advocacy, Spatz Caplan is still fueled by her experiences as a patient and the insights she receives from patient advocacy groups. One project Spatz Caplan is proud of is the STEP (Solutions to Empower Patients) Program™. She wanted to create a program that engages external advocacy organizations in an effort to address gaps in care and unmet patient needs. The pilot launched to help find solutions for people living with metastatic breast cancer as they navigate their treatment path. This year, 3 advocacy groups were funded that initiated innovative programs that help patients and caregivers interpret media coverage on research, provide an online patient navigation portal so patients have easy access to information, and create a financial resource directory for patients. The program has been valued by the community, and this year will focus on another patient community with major gaps in care, sickle cell disease.

In the 5 years since Spatz Caplan joined Novartis, the cancer landscape has continued to evolve as scientists, researchers, patient advocates, and oncologists work together to advance research. “The only way we are going to make it better for other families is to keep studying and researching cancer, and identifying new targets for which new treatments can be developed,” Spatz Caplan says. “I’m working for a company that is a change agent and is looking to invest in making lives better for people impacted by cancer – and that makes me feel like there could be a brighter future for people over time.”

When Spatz Caplan looks back on how her breast cancer diagnosis changed the course of her life in 1991, she is filled with gratitude. “I’m just grateful to be alive and well, and to witness life’s milestones. Twenty-seven years ago, those milestones were so far away.”



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