



# Biomarker Testing in New York: A Storybook

# Introduction

Progress in improving cancer outcomes increasingly involves the use of precision medicine, which uses information about a person's own genes or proteins to prevent, diagnose or treat diseases like cancer. Biomarker testing opens the door to precision medicine, including targeted therapies that can result in improved survivorship and better quality of life for individuals with cancer and other diseases and chronic illnesses. **New York has the opportunity to expand residents' access to this lifesaving testing.** Senate Bill 1196 / Assembly Bill 1673 would make it possible for more patients to get the right treatment at the right time. The following stories highlight the benefit of biomarker testing on patient care.



## Karen Petersen | Harlem

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If not for biomarker testing, I wouldn't be alive today. It opened up the door to a cutting-edge treatment that has given me a fighting chance against my 'terminal' diagnosis

In January 2015 at age 54, Karen Petersen was diagnosed with stage 1 triple-negative breast cancer. Since her tumor was small and had not yet spread, her doctors advised she undergo chemotherapy. Karen also opted for a voluntary double mastectomy so that she wouldn't need radiation. Together, these treatments would lower Karen's chance of recurrence to 4%. Upon recovering from surgery, life returned to 'normal.' This lasted for a little over a year. Then, in April 2017, Karen's cancer returned, spreading to her lungs, ribs, spine and pelvis. She knew then that it was time to take charge of her

treatment plan. Karen read everything she could get her hands on about metastatic triple-negative breast cancer, and her research led her to biomarker testing. Thankfully, she received a grant to cover the testing--the results of which indicated that she was eligible to participate in a clinical trial for an immunotherapy. After several weeks of the therapy, Karen's tumors shrunk by 72% and, within months, they were gone. Karen has been in remission since 2019, soaking up time with friends and family and advocating to ensure that other New Yorkers have access to the testing that saved her life.



## Berta Pesantez | Manhattan

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I was lucky to have received biomarker testing when I did. Everything fell into place for me to gain assistance with its cost and participate in a lifesaving clinical trial. But I want to take luck out of the equation and ensure access to biomarker testing through the law.

Berta Pesantez had all but lost hope when her doctor proposed that she undergo biomarker testing. Berta, 51, was dealing with stage 4 bile duct cancer and running out of treatment options. She was not familiar with biomarker testing; it hadn't been available through the local hospital at which she received chemotherapy and much of her treatment up to that point. With help from a grant program, she was able to undergo the testing. The results of Berta's biomarker testing

revealed that her tumor contained a genetic mutation--one that was being studied in a clinical trial in New York City. Berta jumped at the opportunity to participate in the trial. Within weeks of starting the trial medication, her scans showed a dramatic reduction in her cancer. Berta remains grateful for the assistance that enabled her to receive biomarker testing and is eager to make it so that every New Yorker who can benefit from biomarker testing has access to it.



## Ashley Valentine | Bayville

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Biomarker testing drastically improved my quality of life, allowing me to avoid treatment that could've compromised my cognitive abilities.

In May 2021, Ashley Valentine began experiencing some skin sensitivity and irritation. She consulted a series of doctors, which brought shocking news; Ashley had a fast-moving, aggressive form of cancer known as Acute Myeloid Leukemia. There was consensus among the providers that Ashley had to act as quickly and aggressively as the cancer itself, but her treatment plan wouldn't follow the typical regimen prescribed for Acute Myeloid Leukemia; results from her biomarker testing, which was recommended upon being diagnosed, forced her care team to rethink their approach.

A mutation was discovered through the biopsy of her bone marrow that indicated Ashley was a prime candidate for a transplant, and her brother was a match. The transplant, paired with an oral chemotherapy and targeted therapy, enabled Ashley to enter into remission within months-- where the one-size-fits-all, traditional treatment route would've taken years. Ashley's biomarker testing was covered by her insurance but she did encounter a very high deductible. A financial aid package made it so that Ashley did not incur medical debt as a result of her biomarker testing.



## Joseph Cantafio | West Seneca

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I have three young triplet boys at home. Thanks to the options that biomarker testing gave me, I can continue to be there for them and watch them grow up.

Joe Cantafio was 53 and in the best shape of his life when he came down with a sinus infection that wouldn't quit, lingering for weeks on end despite a course of antibiotics. A CT scan confirmed a blockage in his sinus passage that a quick outpatient procedure would fix. To everyone's surprise, the mass was not a polyp but a vascular mass and very rare cancer; only 50 people in the U.S. has mucosal melanoma, like Joe. Recognizing the severity of this diagnosis and it being uncharted territory for the providers, Joe opted to receive biomarker testing. At first, his insurance would not cover the

testing, but Joe fought for a peer-to-peer review and received approval for coverage. The biomarker testing indicated that Joe had the BRAF marker, which opened up his options. He could receive immunotherapy. There would be risks with this treatment and potential side effects, but it could cure him. Joe decided to pursue it. He is still receiving the immunotherapy infusions every 2 weeks and his condition continues to improve. Joe's doctor recently told him that, 5 years ago, he wouldn't have had a shot at a cure, but, with biomarker testing, he had hope.



## Peter Marinaro | Lagrangeville

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I am grateful that my insurance covered my biomarker testing as it has greatly informed my treatment plan and given me immense hope. Every cancer patient should have similar access to diagnostic and treatment resources—and the hope such resources bring.

At 38-years-old, Peter Marinaro received news that he had cancer—for the second time in his life. As a child, Peter developed and overcame osteosarcoma. Over two decades later, Peter again faced cancer, but this time it was different; he was battling two diagnoses—stage IV colorectal cancer and papillary thyroid carcinoma with evidence of disease in his lymph nodes. Not only was Peter’s diagnosis different from that of his youth but so were his tools to fight it. Upon being diagnosed in October of 2020, Peter’s oncologist recommended that he undergo

biomarker testing. The information gathered from Peter’s biomarker test results gave his oncology team an understanding of the duration and intensity of treatment that was required. For instance, after testing positive for certain biomarkers, it was discovered that Peter would require a more aggressive chemotherapy regimen. In June 2022, Peter was declared "NED," meaning there is presently no evidence of disease. Peter is a proud father to three girls, husband and business owner to which he can dedicate more time and energy thanks, in part, to biomarker testing.



## Kenneth Schlosser | Williamsville

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I get to live a full, active life because of biomarker testing and am able to thrive with cancer. It's made me hopeful for the future; not every cancer patient gets to say that, but they should.

Ken Schlosser began experiencing intense pressure in his chest in March of 2019. What felt like acid reflux or a heart attack was increasingly uncomfortable and not something he'd experienced before, moving Ken to head straight to the ER. He was 58, working full time, happily married and a proud girl dad; the last thing he expected was a serious lung cancer diagnosis. To the shock of Ken, his wife and daughter, it was serious. The young doctor had to convey his diagnosis as stage IV non-small-cell lung cancer with evidence of disease also in his vertebrae and lymph node. His doctors prepared him to undergo intense rounds of chemo and immunotherapy where the side effects would be debilitating and not effective for his mutation. But, before he could

start on the routine treatment course, his doctor recommended that Ken undergo biomarker testing. Ken was on-board, grateful for the opportunity to avoid chemotherapy; however, his employer-sponsored insurance plan wouldn't cover the testing. Before Ken reached into his own pocket to pay for the testing, he learned that the fundraising arm of his comprehensive cancer center would cover the cost as part of a verification process. He would never see a bill for the testing. The results of Ken's biomarker testing indicated that he was a fit for a targeted therapy—a drug he would take twice a day, every day with eight capsules. He has been on that medication since May of 2019 and only has minor side effects. Today, there is no evidence of active disease (NEAD) in Ken's body.





## Giovanna Whitting

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Biomarker testing gave me the 'normal' life I've dreamed of since I was a kid. Any story I tell--about my amazing friends, loving family and college career--will include the crucial role biomarker testing played in my survivorship. I wouldn't be here without it.

When Giovanna Whitting was 8, she began to have trouble breathing, finding discomfort when she exercised and ate. One day over a bowl of Cheerios, Giovanna found that she couldn't swallow. A visit to the ER confirmed the worst; she had a tumor in her throat, which was an aggressive form of thyroid cancer. Four surgeries later, the doctors removed all but 5% of the tumor--the portion of which that was wrapped around her vocal cords. Giovanna was able to return to her childhood, taking medication to regulate her thyroid function. Then, at 16, the cancer spread to her lungs, and the prognosis was not

good. Giovanna thought the end was near; she'd been fighting for so long and wasn't sure she had the energy to keep going. But her family wouldn't accept that. They wouldn't let her give up. Soon after, Giovanna learned about a clinical trial-- participation in which required undergoing biomarker testing. Giovanna underwent the testing and began the trial, taking 2 pills in the morning and 2 more at night. Within a day, her symptoms began to fade; she could breathe again. Now, at 21, Giovanna leads a full life, attending college and relishing the spent time with her family--grateful that they didn't let her give up.