



# Biomarker Testing in Pennsylvania: 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.

**Pennsylvania has the opportunity to expand residents' access to this ground breaking testing.**

Senate Bill 954/ House Bill 1754 would make it possible for more patients to get the right treatment at the right time. The following stories highlight the benefit that biomarker testing has on patient care.



## Giovanna Whitting | State College

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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 Penn State and relishing the spent time with her family--grateful that they didn't let her give up.



## Lisa Selan | Mechanicsburg

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No cancer patient should have to fight a battle without a sense of what exactly they're fighting. Pennsylvania can provide its residents with the roadmap to fight their disease, but we need our state leaders to act.

On February 6, 2020, Lisa Selan was diagnosed with stage II colorectal cancer. She was 53 years old and in good health when she received the news. Fortunately before the pandemic, Lisa was able to undergo surgery to remove her sigmoid colon and 20-some lymph nodes. But, several months after her surgery, Lisa was not recovering at the pace her doctors expected. A series of tests in November of 2020 confirmed her fears; the cancer had metastasized to her liver and was now stage IV. Upon receiving her metastatic diagnosis, Lisa's doctors recommended that she undergo biomarker testing. Lisa was fortunate that she did not incur any expenses from her biomarker testing; her insurance

covered a portion of the testing, and a scholarship covered the rest.

Recognizing that many Pennsylvanians don't have access to biomarker testing either through their health plan or a scholarship, Lisa was grateful that the door to precision medicine was open to her, improving her chance at survival.

The results of Lisa's biomarker testing came back during her first round of chemotherapy. The presence of specific biomarkers motivated her care team to start her on certain targeted therapies, which were key to Lisa reaching remission. It's been nearly two years since Lisa was declared "in remission," and she credits biomarker testing for all the joy she's felt in the intervening time



## Dan Wilson | Chalfont

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When I received the results from biomarker testing, I remember my doctor saying ‘it’s like you won the lottery’. They were right, because of biomarker testing, I received targeted treatment that lead to me being here today.

Dan Wilson was 34-years old when he developed a cold that he couldn’t shake. He didn’t think twice about it, he was active as a college soccer referee and a father to two young kids. After a few months his cough progressed to a point where he couldn’t speak effectively, and he knew something was wrong. Dan’s doctor recommended that he go to the ER at his community hospital. Test after test came back negative until a CT scan showed a mass in his chest that was impacting each lung. The doctors were 90% sure it was cancer, Lymphoma to be specific. Dan panicked – his uncle had passed away when he was just 41-years old from non-Hodgkin Lymphoma.

Due to Dan’s young age and the severity of the situation, he was treated quickly at Jefferson Hospital. His doctor sent his sample through a panel of biomarker tests. He learned that he had the biomarker ALK Positive, present in 3-5% of all non-small cell lung cancer cases. With this information, Dan’s doctor was able to determine the best path forward. After a few courses of radiation treatment, Dan switched to a targeted oral therapy, a pill he could take in the peace of his own home. Two years after starting therapy, Dan received his first stable scan, and has received them ever since. Dan knows that he would not be here today without biomarker testing.





## Summer Farnen | Hershey

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I strongly believe that every patient should advocate for biomarker testing because it is a chance to receive options, answers, and the most effective treatment.

With a father that worked in clinical trials, Summer grew up talking about cancer at the dinner table, but she never thought she would be diagnosed herself one day. Summer's diagnosis came early in the pandemic, and what was originally thought to be asthma turned out to be fluid crushing her lungs. At 44 years old, with no known risk factors, Summer found out that she had lung cancer – on her 21st wedding anniversary. Not a great way to celebrate.

Her doctor explained the importance of biomarker testing in determining any mutations. After some complications with the testing process, Summer received her results a month later: she was ALK+.

Summer's doctor started her on the

standard treatment for ALK+ patients, and while it worked well to attack the cancer, there were negative impacts on her liver. Using the information gained by biomarker testing, she was given a targeted therapy which has made a huge impact on her quality of life over the past 3 years.

In November 2023, Summer had a progression scare after finding a lump on her arm. She knew the first step would be biomarker testing to determine what is driving the cancer. Instead of wasting time, or throwing darts in the dark, biomarker testing can lead to real answers and treatment solutions. Now, Summer is a strong advocate for biomarker testing, speaking with labs, foundations, patients and more.



## Dr. Jennifer Johnson | Sidney Kimmel Cancer Center

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If we allow only some people to access biomarker testing, then we are exacerbating disparities among patients, which is egregious. The idea that some people can get better treatment than others -- Pennsylvania is better than that.

As the Co-Founder and Medical Co-Director of the Precision Medicine Initiative, Dr. Jen Johnson knows that biomarker testing has been one of the biggest improvements to medical oncology. This is because it assists doctors in selecting the right type of treatment for their patients, decreasing potential negative side effects from treatment and improving the patient's quality of life. Dr. Johnson relishes the opportunity to tell patients that because of biomarker testing results they can receive a targeted, specialized cancer treatment option instead of chemotherapy. Simply sharing this news with a patient can reduce fears, relieve an emotional weight, and give them hope for their quality of life.

However, Dr. Johnson recognizes that insurance is a huge barrier to testing. Patients have expressed concern about getting an expensive bill and frustration around the explanation of benefits they receive. At Thomas Jefferson's Sidney Kimmel Cancer Center, Dr. Johnson is fortunate to work with an entire team to help ensure there is minimum billing passed on to patients, but not every health system has the opportunity to do this. Pennsylvania health plans need to keep pace with innovation. Dr. Johnson knows that if doctors do not have access to biomarker testing, then they cannot do their jobs.



## Besty Ulmer | Jenkintown

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Through biomarker testing, my doctor discovered two different mutations of my liver cancer. Instead of undergoing chemo again, I started treatment that targeted the specific mutations.

Betsy Ulmer went to the hospital in the middle of the night due to abdomen pain, thinking she had diverticulitis. It turns out she had liver cancer. For her treatment, Betsy went to the Fox Chase Cancer Center. She underwent two different rounds of chemotherapy and surgery. Unfortunately, despite the aggressive treatment plan, her cancer came back.

This is when her oncologist sent tissue of her tumor out for biomarker testing. She had a IDH1 mutation and was enrolled in a clinical trial for what is now an FDA approved drug. Betsy's doctor described this drug as a 'golden bullet.'

Betsy spent two years seeing progress on this treatment, but then an MRI showed additional tumor growth. Tissues from those tumors were put through biomarker testing again. This round of testing found a secondary mutation, a FGFR2 mutation.

Before Betsy knew it, she was one another FDA approved drug -- one designed to target her cancer mutations specifically. Betsy now only has one nodule remaining. She is thriving thanks to biomarker testing. In the words of her oncologist, 'we can cure metastatic cancers knowing the genetic makeup of tumors.'





## Susan Gordon | York

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**Biomarker testing is the future, it should be used to treat cancer going forward. Knowledge is power.**

Susan comes from a big family and unfortunately, they are no strangers to cancer. Over the years, her relatives have had diagnosis of ovarian cancer and breast cancer, Leukemia and melanoma, and when Susan herself was 33, she was diagnosed with breast cancer. Fortunately, her treatment went well and she reached remission within a year. But 35 years later, in January 2023, she was diagnosed with cancer, again. This time it was ovarian cancer.

Shortly after her diagnosis, her doctor recommended biomarker testing to help determine the most effective treatment. However, her insurance did not cover the cost of this game-changing test. This motivated her care team to help find funding support, which came

through a UPMC Foundation. The multi-panel test assessed 148 genes and determined that Susan had the RAD 51 D gene mutation. With this information, Susan's medical team determined a personalized treatment plan: surgery followed by six months of chemo. This combination led Susan to remission in just 6 months. To prevent the return of her cancer, Susan takes a daily targeted oral chemotherapy, indicated specifically for the gene. Susan sees biomarker testing as critical to her continued survivorship. The discovery of her genetic mutation gave her team insight into how to best fight her unique diagnosis and can serve as an asset in the family's continued health.



## Mike Hu | Philadelphia

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**No one should be denied access to biomarker testing that can put them on the right path to treatment.**

St. Patrick's Day 2022 changed Mike's life forever. This was the day he was diagnosed with stage 4 lung cancer. He had been struggling with back pain for months, but when it escalated to shortness of breath, he went to urgent care. Mike was caught off guard when doctors told him that his back pain was the result of a tumor on his spine. To add to his shock, cancerous lesions had been found on his liver, pancreas, and lungs.

On the day of his diagnosis, a biopsy was ordered along with biomarker testing. His oncologist explained that biomarker testing would help provide a clear direction for treatment. Mike received “good news” one week later; he has the ALK positive biomarker, which would open the door to a number of strong treatment options, which were shown to be effective.

A week later, Mike started his targeted

therapy at home, coupled with radiation to his spine, and he noticed positive impacts right away; his pain dramatically reduced. Mike believes he has biomarker testing to thank for putting him on the path to targeted treatment right, and through such treatment, a decrease in discomfort. While biomarker testing was key to Mike's treatment, his initial coverage claim was denied by insurance because it was not considered ‘standard of care’. Fortunately, he was able to appeal the decision and secure financial support for the life-altering testing. Though Mike never saw a bill for his biomarker testing, he believes it is unjust that insurance is a limiting factor for so many patients battling disease. He believes cost should not be a barrier for any patient seeking targeted treatments.

## Marilyn H | Allegheny County

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When my breast cancer came back in 2022, I knew that the cancer world was different and the tools to fight the disease were improved since my initial diagnosis in 2006. New resources, like biomarker testing, are enabling patients to live longer and with an improved quality of life. With my second diagnosis, I benefitted from these advancements in medical innovation, and biomarker testing played a key role in my survivorship.

Marilyn is a proud single mother and, even through two cancer diagnoses, her commitment to her two children has been her priority. She was 58 when she received her first diagnosis following her annual mammogram. It was with stage II ER+ breast cancer. Through her treatment, which included three lumpectomies and radiation treatment, Marilyn only missed three days of work total and never missed an opportunity to see her children or grandchildren. Upon completing treatment, she was declared cancer-free and returned to ‘normal’ life.

17 years later and her scans continued to show healthy results -- that was

until April of 2022. A CT scan produced the results that every cancer survivor fears; it was back and had metastasized. Marilyn’s oncologist recommended that she undergo some blood tests, which turned out to be biomarker testing. As a Medicare recipient with an advantage plan, her biomarker testing was covered. The results of her biomarker testing directly informed her treatment plan, allowing an aggressive regimen that wouldn’t entail chemotherapy. Marilyn remains grateful that the medical innovation of the intervening 15 years between her two diagnoses enabled her to effectively fight her disease, again.

