



April 29, 2024

Chair Daugherty, Vice Chair Young, and members of the Health and Human Services committee,

On behalf of NMDP (National Marrow Donor Program)—the nonprofit operating the national unrelated donor registry—thank you for the opportunity to submit written testimony in support of S.B. 24-124 which would give more Coloradans access to biomarker testing so that they can get the right treatment for their blood cancer or disorder at the right time.

NMDP supports biomarker testing, which is the analysis of a patient's tissue, blood, or other biospecimen for the presence of a biomarker which helps doctors certify that they are getting patients the most effective treatment for their diagnosis. Not everyone in Colorado is benefiting from the latest advancements in medical treatment due in part to a lack of insurance coverage. S.B. 24-124 will help all Coloradans access biomarker testing if and when they need it.

While most bone marrow or blood cell transplants NMDP facilitates are to treat cancer, they are also a treatment for non-malignant chronic diseases such as aplastic anemia, myelodysplastic syndrome (MDS) and sickle cell disease (SCD). For example, some SCD patients must undergo biomarker testing to determine suitability and eligibility for clinical trials. If a patient's insurance does not cover biomarker testing, the cost may preclude them from accessing the treatment they need.

Biomarker testing can help Coloradans save on healthcare expenses. Comprehensive biomarker testing can aid in identifying treatments with fewer side effects, longer survival rates, and allow patients to bypass treatments that are likely to be ineffective or unnecessary. Avoiding ineffective treatments can also result in cost savings for insurers.

We ask that the committee support the passage of S.B. 24-124 to help more Coloradans access the right treatments in the right amount of time.

Thank you for your consideration,

Jess Knutson

Director, Government Affairs and Public Policy  
NMDP

*About NMDP, as a global nonprofit leader in cell therapy, NMDP creates essential connections between researchers and supporters to inspire action and accelerate innovation to find life-saving cures for blood cancers and disorders. Entrusted by Congress to operate the national registry of the world's most diverse donors and with an extensive network of transplant partners, physicians, and caregivers, NMDP is expanding access to treatment so that every patient can receive their life-saving transplant.*

## Biomarker Bill Committee Testimony Bill 124

Thank you Chair Fields and members of the committee for holding this hearing for Senate Bill 124.

My name is Nancee Pronsati. I live in Golden, Colorado

I am a stage 4 ALK Positive lung cancer patient and have been able to live a wonderful, full life for the last 8 years due to access to biomarker testing. Many stories today will be about the terrible, sometimes deadly consequences of delayed or inaccessible biomarker testing, whether due to doctor's lack of information or insurance denial. I'm testifying for this bill because I believe everyone should be able to have the opportunity to have the same treatment and success as I have had – even after receiving the news that I had a terminal, incurable disease.

My physician was very knowledgeable about lung cancer impacting those who were younger and had no risk factors and immediately ordered not one, but two biomarker tests for me when the first came back that I had no mutation. He was certain that I did. My insurance at the time paid for both tests no question and I was able to start on targeted therapy that has allowed me an amazing quality of life. Financial toxicity is a heavy burden for cancer patients as it is, but allowing insurance companies to deny the only testing that can properly identify treatment is unconscionable.

I'm currently the VP of the Board of ALK Positive, Inc., a non-profit dedicated to extending the lives of patients diagnosed with the ALK genetic mutation. I can't even begin to tell you the stories of people who were unable to access biomarker testing (whether due to insurance denial or a Dr not requesting). The results are often catastrophic even if they ultimately do get the testing - they will have received the wrong treatment altogether or progressed further. The cost of lifesaving testing could be prohibitive for many patients and should always be covered by insurance. In my opinion, guidelines should be changed to require biomarker testing for every cancer diagnosis and insurance should be required to cover this necessary testing.

My request is that everyone have access to the opportunity for the best treatment for their disease. It is not an exaggeration to say that cancer patients will die without it.

Thank you Chair Fields

Nancee Pronsati

Madam Chair and Members of the House Health and Human Services Committee,

My name is Jamie Ellefson, and I live in Littleton. I would like to ask for your support of SB 24-124. I am living proof that biomarker testing has the power to change a patient's course of treatment. I am alive today because of a targeted treatment option that was only revealed because of biomarker testing on my tumor.

I am 47 years old, a Colorado native, married, and have a beautiful 9 year old daughter. I have NEVER smoked and I am a very fit, healthy and active person. I have always been very passionate about health, fitness and the outdoors.

My story begins on July 31, 2021. I became very ill with food poisoning. My primary care doctor initially suspected appendicitis and sent me to the ER. On a CT scan, they happened to catch an image of the bottom of my lungs and found a large nodule in my left lower lung lobe. They didn't know what it was and told me I needed to have it checked immediately. The pulmonologist suspected it was a nodule caused by a bacterial or fungal infection. She tried putting me on a 2 week course of heavy duty antibiotics and then did another CT scan. The nodule remained unchanged.

After a very painful biopsy of the nodule, I received the dreaded phone call telling me that I in fact had NSCLC (non small cell lung cancer). At that point I was considered to have stage 2B lung cancer as it had already metastasized to my lymph nodes. I was immediately referred to a cardiothoracic surgeon for a consultation. I was told I would need to have half of my entire left lung removed surgically, followed by 4 months of chemotherapy. I had surgery October 25, 2021 and then began chemotherapy in Dec 2021 and my last round was March 2022.

The biomarker testing I initially had done on my tumor did not show any genetic mutations driving my cancer. But after seeking a second opinion from Dr. Patil at UcHealth, he ordered much more extensive biomarker testing to be done. I told him that I already had genetic/biomarker testing done and I was told my cancer didn't have a genetic mutation. He educated me on the biomarker/genetic testing process. I learned that there are very different types of testing and it varies greatly depending on what lab you send the sample to and what specific type of testing they perform. He said he wanted to send my tumor sample to the lab at UcHealth because they do very specific testing for very specific genetic mutations.

Within about 2 weeks, the results were back and confirmed what Dr. Patil had suspected, I had RET-positive lung cancer. He told me that finding that information out was extremely important and would change the course of my entire treatment. In fact he said that if we had proceeded with the original course of treatment, the drug they would need to give me if my cancer returned would then not be effective.

I completed my chemotherapy after surgery and had my CT scans and blood work at the end of March 2022 to see if the treatment had worked. The surgery and chemo worked and there was no evidence of disease at that point. I continued with surveillance CT scans and blood work every 3 months to make sure the cancer hadn't returned.

I was considered “No Evidence of Disease” (NED) for about 14 months and then in June 2023, my scans showed that tragically my cancer had returned and I had 3 new tumors in the pleural lining of my chest cavity. I now am considered to have stage 4A terminal cancer. I was immediately put on a drug called Retevmo which is a drug that specifically targets RET-positive cancer cells. I have been on Retevmo since July 2023 and it has been working very well to shrink my tumors and prevent new ones from growing.

If I wouldn't have trusted my gut to get a second opinion and had proceeded with my first oncologist and his treatment plan, I wouldn't be alive today. Dr. Patil truly saved my life by having extensive biomarker testing done on my tumor and finding out the driver of my cancer. If we didn't know I had RET-positive lung cancer, no one would have ever known to put me on the lifesaving drug Retevmo and I wouldn't be alive today to tell my story.

As you can see from my story, biomarker testing for cancer patients is absolutely imperative and has to be done in order to know what is driving the cancer and how to properly treat it. Without it, so many people will be inaccurately diagnosed and treated and potentially die. The health insurance companies must have biomarker testing for cancer patients as a covered benefit. Cancer treatment already financially bleeds a family dry, but adding the stress and cost of biomarker testing shouldn't be another added expense and stress. It is a lifesaving benefit.

During my treatments, my insurance company kept sending me letters and emails saying that “genetic/biomarker testing was not a covered expense” and that I would have to pay out of pocket for it. It costs thousands and thousands of dollars for these tests and there would be no way I could pay for it. I fought them for months and had to have my oncologist send multiple letters saying why I had to have these lifesaving tests done. I spoke with several nurse navigators that work for my health insurance company on multiple occasions explaining why I had to have these tests done and that the cost had to be covered. It was extremely stressful, frustrating and scary during an already horrific time to think that I would likely be responsible for the cost of these tests. I remember sitting up many nights just crying and sobbing and being so scared of what was going to happen. It was an extra awful stress I certainly didn't need while going through surgery and chemotherapy.

Finally after months of fighting my insurance company, they finally decided to cover the costs of the genetic/biomarker testing. It was a true miracle. At the time, there weren't any patient assistance programs available for my biomarker testing. I want to share my story because cancer doesn't discriminate. We all deserve hope and the best treatment options available to us.

Thank you, and I ask for your support of Senate Bill 24-124.

Sincerely,

Jamie Ellefson

**House Health & Human Services**

**05/02/2024 Upon Adjournment**

**SB24-124 Health-Care Coverage for Biomarker Testing**

**Typed Text of Testimony Submitted**

<b>Name, Position, Representing</b>	<b>Typed Text of Testimony</b>
Peggy Dennis  For  themselves	<p>Chairman, Esteemed Members of the Legislative Committee,</p> <p>My name is Peggy Dennis, and I am a living testament to the critical importance of biomarker testing coverage. In 2016, I received a devastating diagnosis of stage 4, non-small cell lung cancer, despite being under 60 and a never-smoker.</p> <p>My doctor recognized the urgency of accessing targeted treatment tailored to my specific biomarkers. However, my insurance denied coverage for these vital tests, creating a barrier to the care I desperately needed. Thanks to the support of Foundation Medicine’s Financial Assistance Program, I was able to undergo biomarker testing which provided an in depth look into what was driving my cancer, alerting my oncologists to the best treatment options available and guiding my cancer care for the last 8 years. But not everyone has the same opportunities for cancer care.</p> <p>Today, I am living proof of the lifesaving impact of comprehensive biomarker testing coverage. It is imperative that we ensure all patients have access to these tests without financial barriers, as they can be the difference between life and death. I urge you to support this bill, so that no one else has to endure the obstacles I faced in accessing lifesaving treatment.</p> <p>Thank you for your time and consideration.</p>

To the Members of the House Health & Human Services Committee,

I am an oncologist providing care to patients in Denver, CO and I additionally serve as the Rocky Mountain Oncology Society Policy Committee Chair. I am writing in support of bill SB24-124 regarding insurance coverage of biomarker testing. The discovery of biomarkers that cause cancer has revolutionized cancer treatment, as treatments have now been developed to target these specific biomarkers, leading to greater efficacy of cancer treatments. This tremendously impacts our patients. To qualify for these treatments, patients must have biomarker testing done to determine if their cancer has these targetable biomarkers. This biomarker testing allows patients to get the best and correct treatment from the beginning of their cancer journey. Without this testing, patients will not be potential candidates for these treatment options and may not receive the best treatment for their specific cancer. The new targeted treatments additionally have proven to help patients with the targeted biomarkers live longer with significantly less toxicity from treatment, thus also improving patients lives while they receive treatment. Requiring insurance coverage of guideline-based biomarker will help patients receive the best treatment for their cancer and help patients live longer with a higher quality of life. Lastly, passing SB24-124 will provide greater health equity for cancer patients. There is evidence indicating that patients who are black, elderly, or Medicaid-insured are less likely to receive the appropriate biomarker testing. Thus, passing SB24-124 and requiring insurance coverage of biomarker testing will provide greater equity in cancer care. Thank you for your time and consideration.

Sincerely,  
Gray Jodon, MD  
Medical Oncology  
Rocky Mountain Oncology Society Policy Committee Chair



May 2, 2024

**RE: SB24-124 Coverage for Biomarker Testing- SUPPORT**

Dear Members of the House Health and Human Services Committee:

Susan G. Komen is pleased to support SB24-124, Health-Care Coverage for Biomarker Testing. SB24-124 provides coverage for biomarker testing to guide treatment decisions if the testing is supported by medical and scientific evidence.

Komen is the world's leading nonprofit breast cancer organization representing the millions of people who have been diagnosed with breast cancer. Komen has an unmatched, comprehensive 360-degree approach to fighting this disease across all fronts—we advocate for patients, drive research breakthroughs, improve access to high quality care, offer direct patient support and empower people with trustworthy information.

Biomarker testing is the analysis of a patient's tissue, blood or other biospecimen for the presence of a biomarker which can provide insight into an individual's medical condition to connect patients to the most effective treatment for their disease.

Biomarker testing is becoming increasingly important in the treatment of cancer and other conditions and is key to matching patients with new targeted therapies which can lead to improved survivorship, better quality of life and often a reduction in health care costs.

For these reasons, Susan G. Komen supports SB24-124 and respectfully urges the committee to pass this critical legislation.

Sincerely,

A handwritten signature in black ink, appearing to read "Lauren Marquette".

Lauren Marquette, LMSW  
Senior Regional Manager, State Policy & Advocacy  
Susan G. Komen