



**THE MICHAEL J. FOX FOUNDATION  
FOR PARKINSON'S RESEARCH**

**Thursday, March 14, 2024  
Colorado Senate Committee on Health & Human Services  
SB24-124 – Health-Care Coverage for Biomarker Testing (SUPPORT)**

Good afternoon, Chair Fields, Vice-Chair Ginal, and members of the committee. My name is Zach Hardy, and I am a State Government Relations Officer for The Michael J. Fox Foundation for Parkinson's Research. Thank you for the opportunity to testify before this committee on **SB24-124**, which would require health benefit plans to provide coverage for biomarker testing.

Founded in 2000, The Michael J. Fox Foundation has been singularly dedicated to finding a cure for Parkinson's disease through an aggressively funded research agenda and to ensuring the development of improved therapies for those living with Parkinson's today. To date, the Foundation has funded nearly \$2 billion in research programs worldwide.

Biomarker testing is a crucial step for accessing precision medicine, including targeted therapies that can lead to improved survivorship and better quality of life for patients. While most current applications of biomarker testing are in oncology and autoimmune diseases, there is research underway to benefit patients in other areas, including neurological diseases such as Parkinson's.

This past April, the Foundation announced that through the ongoing work of our landmark clinical study, Parkinson's Progression Markers Initiative (PPMI), a new biomarker had been identified for Parkinson's disease. This breakthrough was published in the scientific journal *The Lancet Neurology* and opens a new chapter for research, with the promise of a future where every person living with Parkinson's can expect improved care and treatments — and newly diagnosed individuals may never advance to full-blown symptoms.<sup>1</sup>

The Foundation recognizes the importance of biomarker testing and how it will soon broadly benefit our community. There are estimated to be more than 1 million Americans currently living with Parkinson's disease, with about 90,000 more diagnosed each year.<sup>2</sup> According to the Centers for Disease Control and Prevention, Parkinson's disease is the second most common and the fastest-growing neurological disorder worldwide.

In Colorado, there are estimated to be more than 16,400 people currently living with Parkinson's, with direct and indirect costs to care for these individuals estimated to be \$823 million annually. We believe these statistics on prevalence and economic burden to be undercounts.

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<sup>1</sup> "Breaking News: Parkinson's Disease Biomarker Found." The Michael J. Fox Foundation for Parkinson's Research | Parkinson's Disease, 13 Apr. 2023, <https://www.michaeljfox.org/news/breaking-news-parkinsons-disease-biomarker-found>.

<sup>2</sup> "New Study Shows the Incidence of Parkinson's in the U.S. Is Nearly 50 Percent Higher than Previous Estimates." The Michael J. Fox Foundation for Parkinson's Research | Parkinson's Disease, 15 Dec. 2022, <https://www.michaeljfox.org/news/new-study-shows-incidence-parkinsons-us-nearly-50-percent-higher-previous-estimates>.

Improving access to biomarker testing, and thereby access to targeted therapies, is a strategy to reduce health disparities and improve outcomes for patients. This legislation would ensure that coverage requirements for health benefit plans keep pace with innovations in testing, allowing patients to access this critically important health care tool when it is available and medically appropriate.

The Foundation strongly supports expanded access to biomarker testing, as it leads to better treatments and treatments for patients. On behalf of the Foundation and the community that we support, we urge members to support **SB24-124**.

**CONTACT:**

Zach Hardy

State Government Relations Officer

The Michael J. Fox Foundation for Parkinson's Research

[zhardy@michaeljfox.org](mailto:zhardy@michaeljfox.org) — 202-638-4101, Ext. 225



April 11, 2024

Chair Fields, Vice Chair Ginal, 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,

A handwritten signature in black ink, appearing to read "Jess Knutson", written in a cursive style.

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.*

Senator Rhonda Fields  
CC: Members of Senate Health & Human Services  
Colorado Senate  
200 E Colfax Avenue  
Denver, CO 80203

**April 11, 2024**

Chairwoman Fields and Members of the Senate Health & Human Services Committee,

On behalf of the 1.2 million Colorado residents with doctor-diagnosed arthritis, thank you for the opportunity to submit testimony in support of SB24-124, which would allow more Colorado residents to benefit from the most effective treatments for arthritis and other health conditions. This legislation requires insurance coverage for biomarker testing that is supported by medical and scientific evidence, including nationally recognized clinical practice guidelines, for the purposes of diagnosis, treatment, management, or ongoing monitoring of a disease.

Arthritis isn't a single disease; the term refers to joint pain or joint disease, and there are more than 100 types of arthritis and related conditions. People of all ages, races and sexes live with arthritis, and it is the leading cause of disability in the United States. It's most common among women, and although it's not a disease of aging, some types of arthritis occur in older populations and others more predominantly in younger.

**Given the complexity of arthritic diseases and demographics impacted, understanding arthritis is the first step in managing it.** Symptoms of types of arthritis can vary and even be mistaken for other illnesses and disorders, so biomarker testing is an imperative tool to pinpointing diagnosis, prognosis and treatment plans. Considering there are multiple classes of drugs to treat types of arthritis, using biomarker testing can aid in developing precise health plans. Revolutionizing health outcomes through more targeted therapies can lead to improved survivorship and better mobility and quality of life for patients.

Below are some current examples of biomarker testing for patients living with arthritis:

- Polyglutamate testing, which measures methotrexate's effectiveness and can allow a doctor to adjust doses.
- Vectra DA, which is a blood test that measures 12 biomarkers of Rheumatoid Arthritis (RA). The test is *not* used to diagnose RA, but monitors disease activity and can help predict joint damage.

- Anti-CCP2 Test, which selects the cyclic citrullinated peptides (CCPs) that best detect RA, making it more sensitive and specific. It can be used as another tool to help diagnose and manage care for patients living with RA.
- Anti-MCV, which looks for antibodies common in early autoimmune arthritis. It helps to quickly identify RA patients who may present with other forms of arthritis.

Unfortunately, not all communities are benefitting from the latest advancements in biomarker testing, like those listed above. Marginalized communities including communities of color, individuals with lower socioeconomic status, rural communities, and those receiving care in nonacademic medical centers are less likely to receive biomarker testing. Improving coverage for and access to biomarker testing across insurance types is key to reducing these health disparities. Coverage for biomarker testing is failing to keep pace with innovations and advancements in treatment, which is why increasing access is an important component in advancing care options for patients.

The Arthritis Foundation thanks the committee for their consideration of SB24-124 and urges all members to support this critical legislation to expand access to precision medicine for those living with arthritis and other chronic illness patients in Colorado.



Melissa Horn  
Director of State Legislative Affairs  
Arthritis Foundation  
1615 L St. NW Suite 320  
Washington, D.C. 20036  
240.468.7464 | [mhorn@arthritis.org](mailto:mhorn@arthritis.org)



## 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



AdvaMedDx  
Vital Insights | Transforming Care

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February 9, 2024

Honorable Rhonda Fields  
Chair, Committee on Health and Human Services  
Colorado General Assembly  
200 E Colfax Avenue  
Denver, CO 80203

**RE: SB24-124 (Michaelson Jenet) – Support**

Dear Chair Fields:

On behalf of AdvaMed, the MedTech Association, I am writing in support of SB 24 - 124, legislation that will improve patient outcomes by ensuring access to vital biomarker testing.

AdvaMed is the world's largest association representing the full spectrum of medical technology innovators and manufacturers. AdvaMedDx, a division of AdvaMed, represents over 80 manufacturers of *in vitro* diagnostic (IVDs) tests and technologies. Our member companies produce advanced IVD tests and technologies that allow early detection of disease, facilitate evidence-based medicine, improve patient and public health, and enable precision medicine. AdvaMedDx is the only advocacy organization exclusively addressing policy issues facing diagnostic manufacturers in the United States and abroad.

The significance of biomarker testing in patient care cannot be overstated. It is a game-changer in tailoring patient management and prevention plans by integrating individual medical histories and clinical symptoms. This approach is instrumental not just in cancer treatment but also across various medical fields like cardiology, neurology, infectious diseases, and autoimmune disorders. Conditions such as Alzheimer's Disease, Rheumatoid Arthritis, and Preeclampsia are just a few examples where biomarker testing can make a substantial difference.

Unfortunately, current health care coverage for biomarker testing is failing to keep pace with scientific advancements. SB 24-124 aims to bridge this gap by requiring state-regulated health care plans to cover comprehensive biomarker testing when supported by medical and scientific evidence, including nationally recognized clinical practice guidelines. Timely access to



appropriate biomarker testing will result in better health outcomes, advance health equity, and reduce costs. For these reasons, AdvaMed strongly supports SB 24-124.

Your support can transform the landscape of patient care, and we look forward to your leadership in this critical healthcare initiative.

Sincerely,



Zach Rothstein  
Executive Director  
AdvaMedDx



Darbi Gottlieb  
Director, State Government and Regional Affairs  
Advanced Medical Technology Association (AdvaMed)





**AdvaMed**

Advanced Medical Technology Association



**AdvaMedDx**

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March 12, 2024

Honorable Rhonda Fields  
Chair, Committee on Health and Human Services  
Colorado Senate  
200 E Colfax Avenue  
Denver, CO 80203

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Your support can transform the landscape of patient care, and we look forward to your leadership in this critical healthcare initiative.

Sincerely,



Zach Rothstein  
Executive Director  
AdvaMedDx



Darbi Gottlieb  
Director, State Government and Regional Affairs  
Advanced Medical Technology Association (AdvaMed)





*A nonprofit advocacy community  
fighting for treatment for all patients*

Re: SB24-124, Health-Care Coverage for Biomarker Testing

March 12, 2024

Dear Honorable Members of the Colorado Health & Human Services Committee,

On behalf of the infusion patients we represent across the state, thank you for your service and commitment to the people of Colorado. The Infusion Access Foundation is a nonprofit advocacy community and public charity dedicated to ensuring that patients have access to provider-administered therapies for any and all complex diseases. The organization was created to serve as a supportive and inclusive community for the patients receiving these life-changing medications. We are writing in regards to SB24-124. If passed, this bill will require all individual and group health benefit plans in Colorado to provide coverage for biomarker testing to guide treatment decisions, if the testing is supported by medical and scientific evidence.

Precision medicine is dramatically improving health outcomes by using information about a person's own genes or proteins (biomarkers) to prevent, diagnose, or treat [disease](#). Advances in biomarker testing now allow for targeted therapies that can improve patient survival and quality of life. Testing patients for specific biomarkers is integral to precision medicine in cancer care, but despite evidence pointing to the benefits, testing rates lag behind clinical guideline recommendations. Research shows that there are socioeconomic inequalities in biomarker testing and targeted therapy utilization across disease types.

Using the traditional trial and error method, identifying an effective treatment for a particular patient can take months - even years. In chronic, degenerative diseases like rheumatoid arthritis, any length of time spent trying (and failing) ineffective treatments allows the disease to continue causing irreversible damage to the joints, increasing health care consumption and costs. In cancer care and some autoimmune conditions, the length of time it takes to identify an effective treatment can be a matter of life or death. In all cases, ineffective treatments exacerbate the physical, emotional and economic burdens of disease, and the price is paid by both the patient and the insurer.

Health care coverage for biomarker testing is failing to keep up with scientific advancements. Timely access to appropriate biomarker testing will result in better health outcomes, advance health equity, and reduce costs. Please pass SB24-124 and support biomarker testing.

Sincerely,  
Infusion Access Foundation Team

Madam Chair and Members of the Senate 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

Senator Rhonda Fields, Chair  
Senate Health & Human Services Committee  
Colorado State Senate  
200 E Colfax Avenue  
Denver, CO 80203



March 14, 2024

**Support SB24-124 Health-care Coverage for Biomarker Testing**

Madame Chair and Honorable Members of the Senate Committee,

On behalf of Rocky Mountain Cancer Centers (RMCC) we would like to thank you for the opportunity to submit written testimony in **support of SB24-124: Health-care Coverage for Biomarker Testing**. This is an incredibly important step forward in expanding timely access to precision medicine for some of the most vulnerable patients in our state.

For more than 30 years, we at Rocky Mountain Cancer Centers have delivered world-class care to patients across the Colorado Front Range. Because we focus solely on providing state-of-the-art treatment for cancer and diseases of the blood, we're able to bring deep experience and expertise to every personalized treatment plan. Our team of 50+ specialized physicians and 50+ advanced practice providers across 39 locations are impassioned about providing timely access to the most appropriate care directly within the communities where the patients reside. This includes advocating for community-based access to precision medicine for all of the patient populations that we treat.

New advances in precision medicine are rapidly altering the way physicians diagnose and treat cancer. Availability of biomarker testing that factor in a patients' genomic and cellular profile means that truly customized treatments are closer than ever before. As more and more of these targeted therapies are being developed there has also arisen a companion demand for continued access to associated biomarker testing.

Oncologists rely on the ability to identify specific mutations for certain types of malignancies in order to accurately construct a treatment plan that will result in the best possible patient outcomes. They also rely on the ability to continuously re-order these tests in order to maintain assurance that the treatment plan remains appropriate should the patient's disease progress. In conclusion, biomarker testing provides all patients equal access results that can determine the top options for their unique cancer treatment.

Thank you for the opportunity to share our insights. If you have any further questions regarding the impact of enhanced access to biomarker testing for cancer patients, please do not hesitate to reach out. We welcome the opportunity to be a further resource for you. We hope that you will consider joining us in our support for this measure.

Sincerely,

Timothy Murphy, MD  
Practice President  
Rocky Mountain Cancer Centers

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



April 8, 2024

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

Dear Members of the Senate 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 that reads "Lauren Marquette". The signature is fluid and cursive, with a large, sweeping flourish at the end.

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

March 13, 2024

Chair Senator Rhonda Fields  
Vice Chair Senator Joann Ginal  
Colorado Senate Committee on Health and Human Services

**Re: Support for Colorado SB 24-124, Concerning requiring health care coverage for biomarker testing**

Thank you, Chair, Vice-Chair, and members of the committee. On behalf of all ALS patients, including the hundreds of patients we serve in Colorado, we respectfully request your support for SB 24-124. As with many diseases, early detection and treatment are crucial to changing the trajectory of the disease and preventing severe illness or complications, and that is no different with amyotrophic lateral sclerosis. Passage of SB 24-124 will ensure that more people across Colorado can get the life-saving early warning signs through biomarker testing and reduce the long-term burden and the uncertainty of an ALS diagnosis.

Amyotrophic lateral sclerosis (ALS) is a fatal progressive neurodegenerative disease that slowly robs a person's ability to walk, talk, eat, and eventually breathe. The cost of care for someone living with ALS is astronomical, with annual out-of-pocket expenses reaching upwards of \$250,000 per year. The cost associated with biomarker testing should not be added to this financial burden.

Additionally, delays in diagnosis are a significant problem for our community. Many ALS patients go a year or more after symptom onset before being correctly diagnosed. Although there are no known cures or significantly effective treatment options for ALS, early diagnosis is essential in managing the disease, as treatments are liable to be more effective in early disease stages, and earlier detection allows patients and clinicians to anticipate likely complications before they occur.

As new and potentially more effective ALS therapies are being developed and novel biomarkers are being identified, the importance of early diagnosis and biomarker testing coverage will grow significantly. We strongly support the inclusion of biomarker testing in all health insurance plans and Medicaid coverage.

Thank you for your time and your consideration of this critical legislation. For all these reasons, we respectfully request your support for SB 24-124

Sincerely,  
Clark Hansen  
Managing Director of Advocacy  
The ALS Association



OUR VISION: Create a world without ALS.

OUR MISSION: To discover treatments and a cure for ALS, and to serve, advocate for, and empower people affected by ALS to live their lives to the fullest.

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