Corinne Pert Blue Hill, ME 04614

May , 2023

Dear Senator Bailey, Representative Perry, and Members of the Health Coverage, Insurance and Financial Services Committee:

I am testifying in support of LD 1577 - An Act to Require Health Insurance Coverage for Biomarker Testing. Biomarker testing is the reason I am able to be here on earth to write this.

In January 2016 I was diagnosed with stage IV lung cancer. Just months before I went on a multi-day backcountry backpacking trip from rim to river at Grand Canyon, carrying a 30 pound pack. After years in administration, I was happily back in the classroom. Then in fall 2015 I became ill. After three months of illness, doctor appointments, and ER visits, a simple X-ray discovering a mass led (eventually) to my diagnosis. I was a lifelong nonsmoker and very healthy. The cancer was in my left lung hilum and some nodes, and had spread to my liver. When I arrived at Dana-Farber, they immediately began radiation, not as treatment but as palliative care to hopefully shrink the tumor so I could breathe while they were assessing my cancer. I was dying.

Also immediately Biomarker Testing was done. My insurance company denied the testing. What?! I was literally dying. They said since I was in treatment it wasn't needed. I wasn't in treatment, I was receiving palliative care. The radiation was not considered as treatment by the experts treating me. In fact, it did not shrink the tumor, but has left me with fibrosis. Dana-Farber pushed forward, tested, and found I have a gene fusion ROS1 (non hereditary) that is found in only 1% of lung cancer patients. My insurance did eventually pay for the testing, thanks to the work of Dana-Farber advocating for me. In 2016 at Dana-Farber they knew to immediately do biomarker testing on a nonsmoking, healthy woman. Now, Biomarker Testing should be routine and covered by insurance companies. It saves lives. I am proof. I am in a FB group with ROS1 members who are proof.

The research field that includes Biomarker Testing has identified many treatable cancers. For many like me it is the difference between going through weeks, months or years (if you survive) of harsh treatments such as radiation and chemotherapy that may be ineffective. Biomarker Testing and the targeted therapy drugs have increased survival rates by great numbers. I now know what my cancer is. I began a targeted therapy drug when ROS1 was identified and within days my breathing was easier, the tumor was shrinking. When the cancer progressed to my brain meninges 16 months later because the first med didn't protect the brain, the researchers had by then developed a drug that does. I entered a clinical trial in July 2017 and I continue to be on this drug. My cancer is not gone, it is controlled. All thanks to Biomarker Testing. Now I can find joy in the everyday every day.

My Biomarker Testing story is not unique. I have also lost many friends to lung cancer. When you are critically ill or dying with a terminal illness is not the time to have to argue your case with insurance. Biomarker Testing in 2023 should be a routine part of determining next steps for cancer patients. It saves lives and leads to a higher quality of life for patients found to have specific, treatable gene mutations or fusions. For insurance companies to cover this life saving testing only makes sense for our citizens. Thank you for considering LD 1577.

Respectfully,

Corinne Cole Pert

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