

Testimony for the Record

Submitted to the Energy and Commerce Committee

Subcommittee on Health

Hearing Title: “Examining Policies to Enhance Seniors’ Access to Breakthrough Medical Technologies”

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Witness Name: Roger Royse

Witness Organization: None, I testify on behalf of myself.

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Chairman Guthrie and Griffith and Members of the Committee:

Thank you for the opportunity to testify on the importance of increasing access to Medicare coverage of multi-cancer early detection tests (MCED). I appreciate your attention to this important issue.

I am a startup lawyer in Palo Alto, California and am an active member of three non-profit organizations, Cancer Patient Lab, Blood Cancer United (formerly know as the Leukemia & Lymphoma Society), and the Pancreatic Cancer Action Network (PanCan), but I am submitting this written statement on my own behalf as a patient as not as a representative of any entity.

In 2022, I was diagnosed with pancreatic cancer, a disease that only has a 12% 5 year survival rate. Fortunately, I caught it early and as of this summer, my oncologist says that I am now likely cured.

I discovered my cancer from a multi-cancer early detection blood test that I ordered through a telemedicine doctor. At the time of my test, I had no symptoms or obvious signs that anything was wrong. My only risk factor would have been my age (I was 62 years old at the time, placing me within the most prevalent demographic for pancreatic cancer).

According to one radiologist, because of the location of my tumor, and how it was growing, I likely would not have had any symptoms until the last months or weeks of my life. I was extraordinarily lucky to catch it early.

Soon after my MCED test, I encouraged my family to also get tested. Some did, but my brother delayed screening and unfortunately, while I was finishing my final week of chemotherapy, he was admitted for emergency surgery for late-stage lymphoma—a cancer that is highly curable when caught early. My brother died from his cancer nine months later.

I survived a cancer that is 90% fatal; my brother died from a cancer that is 90% curable. My cancer was detected early; his was detected late. My experience and the data support the conclusion that *timing* of detection and treatment is a key factor in recovery.

Pancreatic cancer generally has a dismal prognosis due to the fact that it is usually caught only at a late stage. According to PanCan, the 5 year survival rate has improved slightly over the past decade -- from 7% to 13% -- but pancreatic cancer still remains the third-leading cause of cancer-related deaths in the U.S. and is projected to overtake second place.

Patients diagnosed at localized stages have a much higher survival rate—44%—highlighting the importance of early detection. Despite the importance of early detection in pancreatic cancer, there is no FDA approved screening test for pancreatic cancer. In fact, contrary to modern scientific data, the U.S. Preventive Services Task Force (“Task Force”) twice recommended against pancreatic cancer screening on the grounds that “available screening tests can be invasive, cause pain, and sometimes lead to unnecessary and risky treatment.” That unsupported opinion reflects stale beliefs from twenty years ago. Today cancer can be detected via multi cancer early detection (MCED) techniques that include blood tests (liquid biopsies) and non invasive scans. My own experience with MCED was that it was neither invasive, painful, unnecessary, or risky. It only required a mere blood draw.

Despite the importance and ease of MCED screening, the demographic that needs it most is less likely to be able to afford it. According to the National Cancer Institute (NCI), age is the most important risk factor for cancer since cancer incidence increases with age. Under age 20, for example, there are fewer than 26 cases per 100,000, but for those who are 60 years old or older, there are over 1,000 cases per 100,000. In fact, the median age for cancer diagnosis is 67 years. The cost of my MCED screening was not covered by insurance so I had to pay roughly \$1,000 for the test.

Battling cancer requires constant effort. Patients are not allowed to rest when they are required to advocate for themselves. Even after receiving an early diagnosis, I still underwent 6 months of chemotherapy and a distal pancreatectomy surgery. According to my pathology report, the chemotherapy had no effect so I had to engage in my own research. Eventually, in addition to standard of care, I sought out a novel neo antigen peptide cancer vaccine which was administered under an FDA expanded access program and other supplemental therapies. Cancer patients face a long and uncertain road. Early detection at an affordable cost is the leverage that would help ensure a greater likelihood of survival and lower expenses during the process.

Congress should act to make early detection accessible to more seniors. The Nancy Gardner Sewell Medicare Multi-Cancer Early Detection Screening Coverage Act in particular would be a game-changer, and I encourage Congress to act and make my extraordinary experience ordinary for others.