

March 24, 2022

The Honorable Chuck Schumer  
Majority Leader  
U.S. Senate  
322 Hart Senate Office Building  
Washington, DC 20510

The Honorable Nancy Pelosi  
Speaker  
U.S. House of Representatives  
1236 Longworth House Office Building  
Washington, DC 20515

The Honorable Mitch McConnell  
Minority Leader  
U.S. Senate  
317 Russell Senate Office Building  
Washington, DC 20510

The Honorable Kevin McCarthy  
Minority Leader  
U.S. House of Representatives  
2468 Rayburn House Office Building  
Washington, DC 20515

Dear Majority Leader Schumer, Minority Leader McConnell, Speaker Pelosi, and Minority Leader McCarthy:

On behalf of a broad spectrum of patients, advocacy organizations, cancer centers and healthcare professionals, we are writing today to express our support for the *Reducing Hereditary Cancer Act (H.R. 4110/S.B. 3656)*, legislation that would ensure Medicare beneficiary access to genetic testing for hereditary cancer risk, increased screening and risk reducing interventions, when medically necessary and appropriate.

Under existing Medicare guidelines, only a person with “signs, symptoms, complaints, or personal histories of disease” meets the criteria for coverage of medical services.<sup>1</sup> Recognizing the value of cancer prevention and early detection, in recent years Congress has passed legislation allowing for coverage of certain cancer screenings (e.g., mammograms, colonoscopies and PSA tests) for the “average risk” population.

There has been tremendous progress in cancer prevention, detection, and treatment over the past quarter century. Research shows that inherited genetic mutations play a major role in approximately 10% of cancers, including breast, ovarian, endometrial, prostate, pancreatic and colorectal.<sup>2</sup> Major cancer organizations, genetics, and medical professional societies including the National Comprehensive Cancer Network (NCCN), American Society of Clinical Oncology (ASCO) and others have established guidelines for the assessment and management of hereditary cancer risk.

The U.S. Preventive Services Task Force recognizes the significance of genetics in cancer risk. In 2013, the Task Force published recommendations for *Risk Assessment, Genetic Counseling, and Genetic Testing for BRCA-Related Cancer*. For those with an inherited mutation, the USPSTF notes that management consists of “a variety of interventions to lower future cancer risk. This includes intensive screening, risk-reducing medications, and risk-reducing mastectomy and salpingo-oophorectomy.”<sup>3</sup>

Medicare covers genetic testing only for beneficiaries *already diagnosed with cancer* (regardless of family cancer history or a known genetic mutation in the family). Most private insurers cover genetic counseling and testing for appropriate individuals, including those without a cancer diagnosis, as well as people with a cancer diagnosis. It is crucial that Medicare beneficiaries have access to the same cancer screening and preventive measures as their counterparts with private insurance.

If someone without cancer learns they have an inherited mutation that increases cancer risk (e.g., BRCA1 or BRCA2) prior to Medicare eligibility—or pays out of pocket for genetic testing and finds that they carry an inherited mutation while on Medicare—the individual cannot access the recommended high-risk cancer screenings. Medicare is not permitted to cover these screenings, despite the fact that they are proven to detect cancer earlier, when it is less invasive, less costly, and more easily treated.

Similarly, Medicare is barred from covering potentially lifesaving, risk-reducing procedures, such as bilateral salpingo-oophorectomy (removal ovaries and fallopian tubes). This surgery is crucial for women at high risk of ovarian cancer because there is no reliable screening or early detection; more than 75% of affected women are diagnosed with advanced-stage disease (Stage III or IV).<sup>4</sup> Up to 25% of ovarian cancers are attributable to an inherited genetic mutation. The median age for diagnosis of ovarian cancer in the U.S. is 63 years, meaning almost half of all persons with ovarian cancer are Medicare beneficiaries. Furthermore, those aged 65 or older with ovarian cancer have significantly worse cancer-related survival than younger patients.<sup>5</sup>

Medicare's inability to cover these potentially life-saving tests and interventions exacerbates health disparities. Access to screening and risk-reducing interventions enables early detection and reduces risk for individuals who carry an inherited mutation. We must prioritize screening, early detection, and prevention in Medicare but to do this requires Congressional action. The National Cancer Institute (NCI) predicts nearly 10,000 excess deaths in the U.S. from breast and colorectal cancer alone over the next 10 years because of pandemic-related delays in cancer screening and treatment.<sup>6</sup> Enactment of the *Reducing Hereditary Cancer Act of 2021 (H.R. 4110/S.B. 3656)* will improve access to critical screening and preventive care, and may mitigate some of the predicted cancer-related deaths over the next decade and beyond.

We encourage your support of this lifesaving legislation that will ultimately save Medicare tens of millions of dollars and thank you for your time and consideration today. Please contact [Lisa Schlager](#) at FORCE or [Alyssa Schatz](#) at NCCN with any questions.

Sincerely,

**Patient Advocacy Organizations**

AliveAndKickn

Alliance for Aging Research

Alliance for Patient Access

American Cancer Society Cancer Action Network

Breast Cancer Action

Brem Foundation to Defeat Breast Cancer

Bright Pink  
Cancer ABCs  
CancerCare  
Cancer Support Community  
Colon Cancer Alliance for Research & Education for Lynch Syndrome  
Colon Cancer Coalition  
Community Oncology Alliance Patient Advocacy Network (CPAN)  
DenseBreast-info, Inc.  
Disability Rights Legal Center  
Dr. Susan Love Foundation for Breast Cancer Research  
Fairview Health Services  
Fight Colorectal Cancer  
Florida Breast Cancer Foundation  
FORCE - Facing Our Risk of Cancer Empowered  
Genetic Alliance  
GI Cancers Alliance  
HealthyWomen  
Hereditary Colon Cancer Foundation  
HIS Breast Cancer Awareness  
ICAN, International Cancer Advocacy Network  
ICARE  
Hope For Stomach Cancer  
The Jewish Federations of North America  
Kamie K Preston Hereditary Cancer Foundation  
Let's Win! Pancreatic Cancer  
Living Beyond Breast Cancer  
Living LFS  
Lynch Syndrome International  
Male Breast Cancer Coalition  
National Alliance Against Disparities in Patient Health  
National Coalition for Cancer Survivorship  
National Ovarian Cancer Coalition  
National Patient Advocate Foundation  
NothingPink  
Ovarian Cancer Project  
Ovarian Cancer Research Alliance  
Pancreatic Cancer Action Network  
Prevent Cancer Foundation  
Prostate Cancer Foundation  
Raymond Foundation, Inc.  
Research Advocacy Network  
SHARE Cancer Support  
Sharsheret | The Jewish Breast & Ovarian Cancer Community  
Stupid Cancer, Inc.  
Susan G. Komen  
Thelma D. Jones Breast Cancer Fund  
Tigerlily Foundation  
Triage Cancer  
Us TOO International, Inc.  
Young Survival Coalition  
ZERO - The End of Prostate Cancer

## **Academia/Professional Societies/Medical Institutions**

Abramson Cancer Center, Penn Medicine  
Academy of Oncology Nurse and Patient Navigators (AONN)  
Advocate Aurora Health  
American College of Medical Genetics and Genomics  
American College of Obstetricians and Gynecologists (ACOG)  
American Urological Association  
The American Society of Breast Surgeons  
Association for Clinical Oncology  
Association for Molecular Pathology  
Association of American Cancer Institutes  
Association of Community Cancer Centers (ACCC)  
Basser Center for BRCA, Penn Medicine  
Center for Genomic Interpretation  
Community Oncology Alliance (COA)  
Consortium for Science, Policy & Outcomes, Arizona State University  
Fairview Health Services  
Florida Association of Genetic Counselors  
Fox Chase Cancer Center  
Georgetown Lombardi Comprehensive Cancer Center  
Huntsman Cancer Institute at the University of Utah  
IL Society of Genetic Professionals  
Intermountain Healthcare  
International Society of Nurses in Genetics  
JScreen  
The Lynch Syndrome Screening Network  
MHealth Fairview  
Michigan Cancer Genetics Alliance  
Moffitt Cancer Center  
National Association for Nurse Practitioners in Women's Health  
National Cancer Registrars Association  
National Comprehensive Cancer Network (NCCN)  
National Society of Genetic Counselors  
Northwestern University Feinberg School of Medicine  
Oncology Nursing Society  
Palo Alto Medical Foundation  
Society of Gynecologic Oncology  
Swedish Cancer Institute  
UC Santa Cruz Genomics Institute  
University of Miami  
University of Rochester Medical Center  
US Oncology Network  
William C. Bernstein Familial Cancer Registry, University of Minnesota

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<sup>1</sup> American Society of Clinical Oncology, [Genetic Testing Coverage & Reimbursement](#)

<sup>2</sup> National Cancer Institute, [The Genetics of Cancer](#), Accessed March 22, 2021

<sup>3</sup> JAMA | US Preventive Services Task Force | RECOMMENDATION STATEMENT, [Risk Assessment, Genetic Counseling, and Genetic Testing for BRCA-Related Cancer](#), August 20, 2019

<sup>4</sup> [Am Fam Physician. 2016 Jun 1;93\(11\):937-944](#)

<sup>5</sup> American Cancer Society, [Ovarian Cancer Risk Factors](#), Accessed March 19, 2021

<sup>6</sup> [Sharpless, N. | COVID-19 and Cancer. Science. June 19, 2020](#)