April ##, 2021

The Honorable Nancy Pelosi
Speaker of the House of Representatives
U.S. Capitol Building, H-222
Washington, DC 20515

The Honorable Charles Schumer
Senate Majority Leader
U.S. Capitol Building, S-221
Washington, DC 20510

The Honorable Mitch McConnell
Senate Republican Leader
U.S. Capitol Building, H-230
Washington, DC 20510

The Honorable Kevin McCarthy
House Republican Leader
U.S. Capitol Building, H-204
Washington, DC 20515

Dear Speaker Pelosi, Leader Schumer, Leader McConnell and 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 of 2021*, legislation that would ensure Medicare beneficiary access to genetic testing for 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.[1] 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.[2] 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."[3]

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 already diagnosed with cancer. 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 life-saving, 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).[4] 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. [5]

Medicare's inability to cover these potentially life-saving tests and interventions exacerbates health disparities. Access to screening and risk-reducing interventions enable early detection and reduce 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.[6] Enactment of the *Reducing Hereditary Cancer Act of 2021* 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 and thank you for your time and consideration today. Please contact Lisa Schlager at FORCE or Alyssa Schatz at NCCN with any questions.

FORCE: Facing Our Risk of Cancer Empowered
National Comprehensive Cancer Network

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[1] American Society of Clinical Oncology, Genetic Testing Coverage & Reimbursement
[2] National Cancer Institute, The Genetics of Cancer, Accessed March 22, 2021
[3] JAMA | US Preventive Services Task Force | RECOMMENDATION STATEMENT, Risk Assessment, Genetic Counseling, and Genetic Testing for BRCA-Related Cancer, August 20, 2019
[4] *Am Fam Physician.* 2016 Jun 1;93(11):937-944
[5] American Cancer Society, Ovarian Cancer Risk Factors, Accessed March 19, 2021
[6] Sharpless, N. | COVID-19 and Cancer. Science. June 19, 2020