

March 13, 2023

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

The Honorable Kevin McCarthy  
Speaker  
U.S. House of Representatives  
2468 Rayburn 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 Hakeem Jeffries  
Minority Leader  
U.S. House of Representatives  
2433 Rayburn House Office Building  
Washington, DC 20515

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

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*. This crucial piece of legislation would address unacceptable care gaps in Medicare beneficiary access to genetic testing for hereditary cancer risk, evidence-based 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> For patients with increased hereditary risk of cancer, waiting until signs or symptoms of cancer emerge or a formal cancer diagnosis misses critical opportunities for cancer prevention. 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. The undersigned groups, urge you to take the same action to meet the needs of your constituents on Medicare with increased hereditary risk of cancer.

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* and is currently in the process of developing guidelines for the *Prevention of Lynch Syndrome-Related Cancer*. For those with an inherited BRCA 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> Unfortunately, while this increases access for people with BRCA mutations, it does not address persistent care gaps for people with increased hereditary risk in other mutations. These care gaps exist across testing, screening, and risk-reducing interventions.

**Testing Gaps:** 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.

**Screening Gaps:** If someone without cancer knows they have an inherited mutation increasing their cancer risk, the individual cannot access the recommended high-risk cancer screenings. Under existing law, 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.

**Risk-reducing Intervention Gaps:** Similarly, Medicare is barred from covering potentially lifesaving, risk-reducing procedures, such as bilateral salpingo-oophorectomy (removal of ovaries and fallopian tubes). 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>4</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. Enactment of the *Reducing Hereditary Cancer Act* will improve access to critical screening and preventive care, save lives, and reduce the cancer burden.

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.

Sincerely,

**Patient Advocacy Organizations**

- AliveAndKickn
- Alliance for Aging Research
- American Cancer Society Cancer Action Network
- Black Health Matters
- BRCA Research & Cure Alliance (CureBRCA)
- Breast Cancer Action
- Brem Foundation to Defeat Breast Cancer
- Bright Pink
- Cancer Resource Centers of Mendocino Co
- Cancer Support Community
- Cancer Support Community SF Bay Area

CancerCare  
Colon Cancer Alliance for Research & Education for Lynch Syndrome  
Colorectal Cancer Alliance  
DenseBreast-info, Inc.  
Dia de la Mujer Latina  
Disability Rights Legal Center  
Fight Colorectal Cancer  
For the Breast of Us  
FORCE: Facing Our Risk of Cancer Empowered  
Genetic Alliance  
GI Cancers Alliance  
HealthyWomen  
Hereditary Colon Cancer Foundation  
HIS Breast Cancer Awareness  
Hope for Stomach Cancer  
Let's Win! Pancreatic Cancer  
Living Beyond Breast Cancer  
Male Breast Cancer Global Alliance  
National Coalition for Cancer Survivorship  
National Ovarian Cancer Coalition  
National Pancreas Foundation  
National Patient Advocate Foundation  
Not Putting on a Shirt  
NothingPink  
Nueva Vida, Inc.  
Ovarian Cancer Project  
Ovarian Cancer Research Alliance  
Patient Empowerment Network  
Prevent Cancer Foundation  
Project Life  
Prostate Cancer Foundation  
PTEN World  
Raymond Foundation  
San Francisco Women's Cancer Network  
Sharsheret | The Jewish Breast & Ovarian Cancer Community  
Stupid Cancer  
Susan G. Komen  
Teen Cancer America  
The Chrysalis Initiative  
The Latino Cancer Institute  
Tigerlily Foundation  
Triage Cancer  
Unite For HER  
Vision y Compromiso  
Young Survival Coalition  
Zero Breast Cancer  
ZERO Prostate Cancer

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

Academy of Oncology Nurse & Patient Navigators  
Advocate Health  
AdvocateAurora Health  
Alliance for Innovation on Maternal Health  
American College of Medical Genetics and Genomics  
American College of Obstetricians and Gynecologists  
American Urological Association  
Arizona State University  
Arthur G. James Cancer Hospital and Solove Research Institute - Ohio State University Comprehensive Cancer Center  
Association for Clinical Oncology (ASCO)  
Association for Molecular Pathology  
Association of American Cancer Institutes  
Association of Community Cancer Centers  
Atrium Health Wake Forest Baptist  
Basser Center for BRCA, Penn Medicine  
David Geffen School of Medicine at UCLA  
Florida Association of Genetic Counselors  
Fox Chase Cancer Center  
Fred Hutchinson Cancer Center  
Georgetown University/Lombardi Comprehensive Cancer Center  
Huntsman Cancer Institute  
Illinois Society of Genetic Professionals  
InformedDNA  
Inova Saville Cancer Screening and Prevention Center  
Intermountain Healthcare  
JScreen  
Mayberry Memorial  
MHealth Fairview, University of Minnesota  
Michigan Cancer Genetics Alliance  
Moffitt Cancer Center  
My Gene Counsel  
National Association of Nurse Practitioners in Women's Health (NPWH)  
National Cancer Registrars Association  
National Comprehensive Cancer Network  
National Society of Genetic Counselors  
Northwestern Medicine  
Ohio Association of Genetic Counselors  
Oncology Nursing Society  
Palo Alto Medical Foundation  
Sanford R. Weiss, MD Center for Hereditary Colorectal Neoplasia, Cleveland Clinic Foundation  
Society of Gynecologic Oncology  
Stanford University School of Medicine  
Texas Oncology  
The American Society of Breast Surgeons  
The US Oncology Network  
TriHealth

UC Santa Cruz Genomics Institute  
UCLA Health  
UCSF Breast Science Advocacy Core  
UCSF Helen Diller Family Comprehensive Cancer Center  
University of Florida Health Cancer Center  
University of Miami Sylvester Comprehensive Cancer Center  
University of Rochester Medical Center  
William C. Bernstein MD Family 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> American Cancer Society, [Ovarian Cancer Risk Factors](#), Accessed March 19, 2021