July ##, 2025

The Honorable John Thune
Majority Leader
U.S. Senate

The Honorable Mike Johnson
Speaker
U.S. House of Representatives

The Honorable Charles Schumer
Minority Leader
U.S. Senate

The Honorable Hakeem Jeffries
Minority Leader
U.S. House of Representatives

Dear Majority Leader Thune, Minority Leader Schumer, Speaker Johnson, and Minority Leader Jeffries:

On behalf of a diverse group of patients, advocacy organizations, cancer centers and healthcare professionals, we are writing today to express our strong support for the *Reducing Hereditary Cancer Act*. This vital legislation aims to address significant gaps in Medicare beneficiary coverage of 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.[1] This approach misses critical opportunities for cancer prevention for beneficiaries at increased risk of hereditary cancer. For those with an increased hereditary cancer risk, waiting until signs or symptoms of cancer appear or until a formal cancer diagnosis is made misses critical opportunities for prevention or early detection.

Recognizing the value of cancer prevention and early detection, Congress has previously passed legislation allowing coverage of certain cancer screenings (e.g., mammograms, colonoscopies and PSA tests) for the "average risk" population. We urge you to take the same action to meet the needs of your Medicare constituents with increased hereditary cancer risk.

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 assessing and managing 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 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."[3] 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). 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 the same access to cancer screening and preventive measures as those 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) for individuals with identified hereditary cancer risk. 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.[4,5]

**Cost Effectiveness:** An independent economic analysis of the Reducing Hereditary Cancer Act demonstrates a Medicare savings of $230 million for the 2025 cohort. Similar savings are expected with the entrance of future annual cohorts. Coverage of the guideline-recommended genetic counseling and testing, followed by increased screening and/or risk-reducing interventions for those who test positive, will result in significant healthcare cost savings.

Medicare's inability to cover these potentially life-saving tests and interventions is deeply concerning. 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; this requires Congressional action. Enactment of the *Reducing Hereditary Cancer Act* will improve access to critical screening and preventive care and reduce the cancer burden while saving lives and money.

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**
AliveAndKick'n
Alliance for Aging Research
Alliance for Patient Access
Alliance for Women's Health and Prevention
American Cancer Society Cancer Action Network
Biomarker Collaborative
Black Health Matters
BRCA Research & Cure Alliance

Brem Foundation to Defeat Breast Cancer
Bright Pink
Cancer Support Community
Cancer*Care*
Colon Cancer Alliance for Research & Education for Lynch Syndrome
Colon Cancer Coalition | Get Your Rear in Gear
Colorectal Cancer Alliance
Community Oncology Alliance Patient Advocacy Network
The Chrysalis Initiative
Debbie's Dream Foundation
DenseBreast-info, Inc.
Dia de la Mujer Latina
Disability Rights Legal Center
Exon 20 Group
Families Fighting Hereditary Cancer
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
ICAN, International Cancer Advocacy Network
Kamie K Preston Hereditary Cancer Foundation
Let's Win! Pancreatic Cancer
Living Beyond Breast Cancer
Male Breast Cancer Global Alliance
Mayberry Memorial
MET Crusaders
My Faulty Gene
National Alliance of State Prostate Cancer Coalitions
National Coalition for Cancer Survivorship
National Ovarian Cancer Coalition
National Pancreas Foundation
National Patient Advocate Foundation
No Stomach for Cancer
Not Putting on a Shirt
NothingPink
Nueva Vida, Inc.
Ovarian Cancer Project
Ovarian Cancer Research Alliance
Pancreatic Cancer Action Network
Patient Empowerment Network
PDL1 Amplifieds

Prevent Cancer Foundation
Project Life
Prostate Cancer Foundation
PTEN World
Raymond Foundation
SHARE Cancer Support
Sharsheret | The Jewish Breast & Ovarian Cancer Community
Stupid Cancer
Susan G. Komen
Teen Cancer America
Tigerlily Foundation
TOUCH Black Breast Cancer Alliance
Triage Cancer
Unite For HER
Young Survival Coalition
ZERO Prostate Cancer

**Academia/Professional Societies/Medical Institutions**
Academy of Oncology Nurse & Patient Navigators
American Association of Clinical Urologists
American College of Gastroenterology
American College of Medical Genetics and Genomics
American College of Obstetricians and Gynecologists
The American Society of Breast Surgeons
American Urological Association
Association for Clinical Oncology
Association for Molecular Pathology
Association of American Cancer Institutes
Association of Community Cancer Centers
Basser Center for BRCA, Penn Medicine
City of Hope
Dana-Farber Cancer Institute
Duke Cancer Institute
Fox Chase Cancer Center
Georgetown University/Lombardi Comprehensive Cancer Center
Illinois Society of Genetics Professionals
InformedDNA
Inova Saville Cancer Screening and Prevention Center
Inova Schar Cancer Institute
JScreen
Legacy Health
Michigan Cancer Genetics Alliance
Moffitt Cancer Center
My Gene Counsel
National Association of Nurse Practitioners in Women's Health
National Cancer Registrars Association

National Comprehensive Cancer Network
National Consortium of Breast Centers
National Society of Genetic Counselors
Northwestern University, Graduate Program in Genetic Counseling
Oncology Nursing Society
Roswell Park Comprehensive Cancer Center
Society of Gynecologic Oncology
Stanford Health
Stanford University School of Medicine
TriHealth
UC Santa Cruz Genomics Institute
UCLA Health
The University of Florida Health Cancer Center
University of Miami Sylvester Comprehensive Cancer Center
The US Oncology Network
William C. Bernstein MD Family Cancer Registry, University of Minnesota

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[1] American Society of Clinical Oncology, Genetic Testing Coverage & Reimbursement, Accessed March 3, 2025
[2] National Cancer Institute, The Genetics of Cancer, Accessed March 3, 2025
[3] JAMA | US Preventive Services Task Force | RECOMMENDATION STATEMENT, Risk Assessment, Genetic Counseling, and Genetic Testing for *BRCA*-Related Cancer, August 20, 2019
[4] American Cancer Society, Ovarian Cancer Fact Sheet, Accessed March 3, 2025
[5] Linda R. Duska et al., Epithelial Ovarian Cancer in Older Women: Defining the Best Management Approach. *Am Soc Clin Oncol Educ Book* **35**, e311-e321(2015). DOI:10.14694/EdBook_AM.2015.35.e311