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.[1] 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.[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* 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."[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). 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.[4]

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

Cancer*Care*
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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[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] American Cancer Society, Ovarian Cancer Risk Factors, Accessed March 19, 2021