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

The Honorable Mitch McConnell Minority Leader U.S. Senate 317 Russell 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 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 <u>Lisa Schlager</u> at FORCE or <u>Alyssa Schatz</u> 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

¹ American Society of Clinical Oncology, <u>Genetic Testing Coverage & Reimbursement</u>

² National Cancer Institute, <u>The Genetics of Cancer</u>, Accessed March 22, 2021

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

⁴ American Cancer Society, <u>Ovarian Cancer Risk Factors</u>, Accessed March 19, 2021