November 14, 2024

The Honorable Mike Johnson Speaker of the House United States House of Representatives Washington, D.C. 20515

The Honorable Hakeem Jeffries House Minority Leader United States House of Representatives Washington, D.C. 20515 The Honorable Chuck Schumer Senate Majority Leader United States Senate Washington, D.C. 20515

The Honorable Mitch McConnell Senate Minority Leader United States Senate Washington, D.C. 20515

Dear Speaker Johnson, House Minority Leader Jeffries, Majority Leader Schumer, and Senate Minority Leader McConnell:

On behalf of the nearly 500 undersigned organizations, inclusive of patient advocacy organizations, health care providers and health systems, genetic counselors, and genetic counseling graduate programs, we urge Congress to include, in an end-of-year legislative package, legislation that would recognize genetic counselors as providers in the Medicare program, thereby increasing access to critical genetic counseling services. S. 2323/H.R. 3876, the Access to Genetic Counselor Services Act, takes a measured approach to modernize Medicare to catch up with the innovation of genetics and genomic medicine.

Genetic counselors are healthcare professionals with specialized graduate degrees in medical genetics and counseling, a profession that emerged in the early 1970s as genetics became better understood and diagnostic options expanded. They play a critical role in the healthcare system by partnering with patients and providers across various disciplines. Particularly vital for Medicare beneficiaries with cancer, cardiovascular disease, renal and neurological disorders, genetic counselors help patients navigate genetic testing options and facilitate communication among healthcare providers managing genetic health issues. Ultimately, they empower both patients and providers to make informed decisions.

To ensure that the promise of genetic medicine is fully realized, public policy must support the integration of genetic counselors into the healthcare system, starting with the Medicare program. Many commercial health plans already cover and reimburse genetic counselors, as research shows that their involvement leads to improved outcomes in both quality and cost. Currently, Medicare reimburses genetic counseling when provided by other Medicare practitioners. By recognizing genetic counselors as practitioners, Medicare could potentially save billions through the appropriate utilization of genomic testing.² This legislation will enable the Medicare program to reimburse genetic counselors directly, thereby improving everyone's access to their services.

¹ Precision Medicine Hinges On Access To Genetic Counselors | Health Affairs

² Genetic Counselors Save Costs Across the Genetic Testing Spectrum

Enacting federal legislation to recognize genetic counselors as Medicare providers is essential to guarantee beneficiaries access to high-quality genetic services. We look forward to working with you to ensure that our nation's genetic counselors are acknowledged as integral practitioners of the healthcare system, allowing patients to access their expertise.

Thank you for your consideration.

Respectfully,

Academic Medical Center

Columbia University Irving Medical Center City of Hope National Medical Center Columbia University Irving Medical Center Department of Human Genetics, Emory

University

Emory School of Medicine Johns Hopkins Medicine Kennedy Krieger Institute Long Island University Post

MD Anderson Cancer Center Cooper The University of Texas MD Anderson

Cancer Center UTHealth Houston Graduate

School of Biomedical Sciences University of Arkansas for Medical

Sciences, Department of Genetic Counseling

University of Buffalo University of Iowa

University of Maryland School of Medicine

University of Utah Health

Vanderbilt University Medical Center

Weill Cornell Medicine

Yale University, School of Medicine

Clinician Group

ACT Genetics PLLC

American Society for Reproductive

Medicine

Arizona Genetics Alliance Cancer Partners of Nebraska

CARTI

Chicago Genetic Consultants, LLC

Compass Oncology

Division of Genetics, Department of

Pediatrics. UCSD

Florida Association of Genetic Counselors

Genetic Support Foundation

Genome Medical

GeriatRx

Greenwood Genetic Center

Grow Therapy HealthyGene

Human Genetics Association of New Jersey Invision Sally Jobe / Radiology Imaging

Associates Jscreen

Kaiona Counseling

Maryland oncology hematology Medical Students for Choice

Minnesota Oncology

MKGenetix

National Association of Nurse Practitioners

in Women's Health

Nebraska Hematology-Oncology North Carolina Medical Genetics

Association

Northern Nevada Genetic Counseling Organization of Teratology Information

Specialists

Orlando Health Cancer Institute

Pallister Genetics

Pregnancy Specialty Center of Texas

Self Employed

The US Oncology Network Virginia Cancer Specialists

Virginia Chapter of the American College of

Cardiology Watershed DNA

Graduate Program

Bay Path University Boston University Emory University

Long Island University Post

MGH Institute of Health Professions

Northwestern University Sarah Lawerence College

University of North Carolina Greensboro

University of South Carolina University of South Florida Wake Forest University

Xavier University of Louisiana

Health System/Hospital

Baystate Health

Blank Children's Hospital - UnityPoint

Health

Children's Healthcare of Atlanta Cardiology

CARTI

Genetic Support Foundation GO2 for Lung Cancer Good Samaritan hospital Grady Health System

Lewis Cancer & Research Pavilion

Mass General Brigham

Mercy Health

Memorial Health University

NYC Health+Hospitals Metropolitan

Piedmont Healthcare Seattle Children's Hospital Shodair Children's Hospital

Sutter Health UnityPoint Health

UnityPoint Health- John Stoddard Cancer

Center

UPMC Hillman Cancer Center

Winchester Hospital

Industry

Alexion, AstraZeneca Rare Disease

Color Health

Coriell Life Sciences

Exact Sciences

Genescreen

Genomenon

IVIRMA

Labcorp

Monica Weldon Consulting LLC

MyOme Natera

National Society of Genetic Counselors

Nest Genomics
Olivia's Light, Inc
Quest Diagnostics
Relevant Genetics, LLC

Sanofi

Statmetrics LLC

xCures

Patient Group

AliveandKick'n

ALS Association

American Kidney Fund

Association for Creatine Deficiencies

Avery's Hope

BRCA Responder

Cancer Resource Foundation,

Cancer1Source

CHops Syndrome GLobal

Choroideremia Research Foundation

Coalition to Cure CHD2 Colon Cancer Coalition Colorectal Cancer Alliance

COMBINEDBrain CSNK2A1 Foundation CSNK2B Foundation

CTNNB1 Connect and Cure

Cure CMD

CURE GABA-A

Cure GM1 Foundation

Cure VCP Disease

CureGRIN Foundation

DCM Foundation

Down Syndrome Association of Central

Ohio

Down Syndrome Association of Northeast

Ohio

ElevateDD

EveryLife Foundation for Rare Diseases

Fight Colorectal Cancer

Flok Health

FOD Family Support Group

Foundation for Angelman Syndrome

Therapeutics

GABA-A Alliance

Georgia Center for Oncology Research and

Education (Georgia CORE)

GI Cancers Alliance

HCU Network America

ICAN, International Cancer Advocacy

Network

Immune Deficiency Foundation

Jacqueline Rush Foundation

Kabuki Syndrome Foundation

KCNQ2 Cure Alliance

Les Turner ALS Foundation

Li Fraumeni Syndrome Association.org

Malan Syndrome Foundation

Muscular Dystrophy Association

National Organization for Rare Disorders

No Stomach For Cancer

NW Rare Disease Coalition

Parent Project Muscular Dystrophy

Personalized Medicine Coalition

Project Alive

Raymond Foundation

Remember the Girls

RUNX1 Research Program (RRP)

SATB2 Gene Foundation

Sharsheret

STXBP1 Foundation

Susan G. Komen

SynGAP Research Fund, dba Curesyngap1

Tatton Brown Rahman Syndrome (TBRS)

Community

TESS Research Foundation

The Ehlers-Danlos Society

United Leukodystrophy Foundation

United MSD Foundation

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