



The Honorable Neil Breslin
New York State Senate
Legislative Office Building
Room 806
Albany, NY 12247

Contact Information:
Greenberg Traurig, LLP
518.689.1427
PhelpsW@gtlaw.com
MadeirosP@gtlaw.com
BosworthL@gtlaw.com

The Honorable Linda B. Rosenthal
New York State Assembly
Legislative Office Building
Room 627
Albany, NY 12248

Dear Senator Breslin and Assemblymember Rosenthal,

We are writing to indicate our support of S.5355/A.2151 that would establish genetic counseling as a licensed profession in New York State. Genetic counselors are trained by completing a master's degree at an accredited graduate program and passing a certification exam administered by the American Board of Genetic Counseling (ABGC). They are healthcare providers who guide patients on every aspect of genetic testing, including determining what testing may be appropriate, assessing risk for genetic conditions based on family and medical history, and helping patients and their families understand and adapt to those risks by recommending changes in medical management based on national screening guidelines.

Genetics and genomics are becoming increasingly more integrated into clinical practice. The Affordable Care Act, as well as several major private insurers, including Cigna, United Healthcare, Magnacare, Empire BCBS, and Aetna, have now mandated genetic counseling prior to covering specific genetic tests.

Licensure will help to ensure that qualified and board certified genetic counselors are available to confirm that the genetic testing being ordered is appropriate and essential, reducing the costs and waste associated with superfluous and fraudulent testing. Several studies have established that genetic testing requests made by licensed but non-genetics professionals are at times ordered incorrectly, leading to erroneous and often excess charging of patients and health insurances for genetic testing. In one of the largest publications to date describing the impact of retrospective test review by a genetic counselor in a commercial genetic testing laboratory over a 21-month period, 26% of the test orders were later revised, leading to healthcare savings of nearly \$1.2 million. Several similarly constructed studies have obtained equally staggering results, including healthcare savings of:

- Greater than \$1.24 million on tests reviewed by a genetic counselor over a 6-month period (Londre et al. 2017),
- An average healthcare savings of \$118,952, or \$463 per test, on tests reviewed over an 8-month period (Dickerson et al. 2014),
- \$779,060 on tests reviewed over a 12-month period (Kotzer et al. 2014),
- and \$130,506 on 44 whole exome sequencing tests ordered over a 12-month period and chosen for review because reimbursement was not fully provided by insurance for those tests (Conway et al. 2020)

The majority of tests that were incorrectly ordered were more comprehensive and therefore more expensive than necessary, justifying the cost-effectiveness and efficiency of review of genetic testing

orders by a genetic counselor with expertise in which targeted test is appropriate, given a patient's medical and family history.

Licensure will lead to better recognition by health care insurers, including the Centers for Medicare and Medicaid Services (CMS), an important step in the process which will help assure adequate reimbursement for essential genetics services and access for historically underserved populations by enabling the hiring of additional genetic counselors. Genetic counselors working in NYS will be able to identify and coordinate genetic testing for NYS residents on Medicare, as well as residents falling in a lower income bracket, with disabilities, or living in an area where genetic counselors are not employed. Sixty-seven percent of genetic counselors and 77% of medical geneticists in NYS work in the five boroughs of New York City and Long Island, leaving Central, Northern and Western NYS significantly underserved. Licensure of genetic counselors will allow for the establishment of genetic counseling practices outside of major medical centers in metropolitan areas.

Beyond providing recommendations, interpretation and counseling regarding genetic testing results in the clinical setting, genetic counselors are involved in cutting-edge translational research efforts. Genetic counselors in this setting help to consent research participants, interpret genetic information, and connect with healthcare providers worldwide in order to discover new gene-disease associations, as well as how some genes may influence the way individuals react to historically complex variables such as medications or their environment. Genetic counselors are an important part of the greater precision medicine effort that is globally informing the way individuals are tested for susceptibilities to different illnesses, as well as the efficacy of medications for those illnesses. Licensure will help to establish genetic counselors as recognized healthcare providers in these efforts, securing a place for NYS as a supporter in the forward movement of genomic medicine nationally.

With the increasing impact of genetics and genomic research in standard clinical care and access to genetic testing for the general population, genetic counseling is one of the top growing fields. The U.S. Bureau of Labor and Statistics projects the employment of genetic counselors to grow 27 percent from 2018 to 2028, much faster than the average for all occupations. This increase in demand for genetic counselors will mean the population of genetic counselors in NYS will be crucial to the economic growth of NYS.

Licensure will create clear educational, certification, and continuing education standards for all genetic counselors in the state. Licensure will improve public safety by preventing unqualified practitioners from identifying as genetic counselors and providing incorrect genetic testing and management recommendations, or providing testing without appropriate informed consent in both clinical and research settings. The title "Genetic Counselor" will be used only by those who meet high standards of training, clinical experience and ongoing professional development.

New York has been at the forefront of genetic counseling education for 45 years, but has lagged behind many states in providing for the licensure of these healthcare professionals. Currently, genetic counselors in most of the surrounding states in the northeast including New Jersey, Connecticut, Delaware, Pennsylvania, Massachusetts and New Hampshire have licensure. There are 26 states that currently license genetic counselors, and three additional states in which recent bills have been passed to do so. NYS is home to the nation's oldest and largest genetic counseling program, the Joan H. Marks Human Genetics Program based at Sarah Lawrence College in Bronxville. This program has graduated more than 1,000 genetic counselors since 1969. We are also home to the Icahn School of Medicine at Mount Sinai, the Long Island University Post, and the Columbia University Genetic Counseling programs. Together the clinical training network for these programs encompasses over 60 facilities in NYS, New Jersey and Connecticut. These training programs rely on a network of experienced local genetic counselors for clinical training and supervision of students. Increasing the number of licensed genetic counselors in New York will ensure the survival of these vital programs and will pave the way for additional training programs in the state.

Genetic counselors touch the lives of thousands of NYS residents through their important work. It is imperative to ensure that those who are providing these services are held to the highest standards.

Sincerely,

**Canavan's Disease
Foundation**

**The Brooklyn Hospital
Center**

**Ovarian Cancer Research
Fund Alliance (OCRFA)**

**The Cancer Institute at St.
Francis Hospital**

**Westchester Institute for
Human Development**

**SUNY Upstate University
Medical Center**

Columbia University

White Plains Hospital

Weill Cornell Medical

Cystic Fibrosis Foundation

Sarah Lawrence College

Positive Exposure

Progenity, Inc.

Integrated Genetics

GenePeeks

Ambry Genetics

Natera, Inc.

Genetic Counseling Services

**FORCE: Facing Our Risk of
Cancer Empowered**

**New York–
Presbyterian
Lawrence Hospital**

**Memorial Sloan Kettering
Cancer Center**

Genetic Alliance

**New York University
School of Medicine**

**Richmond Community
Services**

**Quest Diagnostics
Roswell Park Cancer
Institute**

**Northern Westchester
Hospital / Northwell
Health**

**Staten Island University
Hospital**

**Ferre Institute/Ferre
Genetics**

**NTD Eurofins
Clinical Diagnostics**

Windsong Radiology Group

Montefiore Medical Center

The following organizations
provided their own letters in
support of licensure for
genetic counselors in NYS:

Madonna Perinatal Services

Mount Sinai Beth Israel

**National Society of
Genetic Counselors**

**NYS Academy of Family
Physicians**

**Tell Every Amazing Lady
about Ovarian Cancer Louisa
M. McGregor Ovarian
Cancer Foundation**

**Huntington's Disease
Society of America**

**NYS American Academy of
Pediatrics, A Coalition of
Chapters 1, 2, &3**

**Women & Children's
Hospital of Buffalo**

**NYS Genetics Task
Force Board**

University of Rochester

**Hermansky-Pudlak
Syndrome Network**

**Familial
Hypercholesterolemia
Foundation**

**International WAGR
Foundation**

**C.R. Wood Cancer Center at
Glens Falls Hospital**

**Children's Tumor
Foundation**

CdLS Foundation

**Icahn School of Medicine at
Mount Sinai Master of
Science in Genetic
Counseling Program**

**Long Island University Post
Genetic Counseling
Graduate Program**

PWN Health

AXYS Society

**Columbia University Irving
Medical Center Master's
Program in Genetic
Counseling**

**Friedrich's Ataxia Research
Alliance**

Gigi's Playhouse

AliveAndKickn

Cure HHT