



THE STURGE-WEBER FOUNDATION

The stronger the wind, the tougher the trees.

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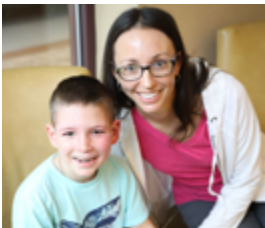
10/31/2023



On behalf of The Sturge-Weber Foundation, we urge you to support bill S.5355/A.2151 for the professional licensing of genetic counselors in New York State.



New York has been at the forefront of genetic counseling education since its inception. It is home to the nation's oldest and largest genetic counseling program and comprises four graduate programs to train future genetic counselors. The four programs in NY are estimated to train approximately 15% of graduating genetic counselors annually. Unfortunately, lack of licensing is a disincentive for individuals trained in NY to remain in the state.



- genetic counselors play a critical role in helping individuals who are concerned about their personal or family history make medical decisions about how to manage their genetic health risks.



- genetic counselors help select the appropriate genetic testing strategy for patients' diagnostic pursuits.

- genetic counselors assist in the interpretation and disclosure of genetic test results to ensure they are maximally utilized and incorporated into patient care.



- genetic counselors help patients to communicate with their family members regarding their own risks in what are often stressful and emotional situations.

- genetic counselors play a critical role in patient education.

- genetic counselors educate patients about rare disease advocacy organizations and clinical research opportunities.



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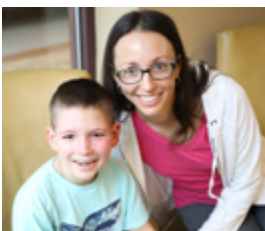
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- genetic counselors help patients navigate the healthcare system by providing targeted and appropriate referrals to specialists, therapists, support groups and other patient resources.
- genetic counselors often help to end the diagnostic odyssey that certain patients with rare conditions have been through in searching for a diagnosis.



The benefits of genetic counseling are numerous, including an improvement in patient knowledge, a more accurate perception of genetic health risks, better psychosocial outcomes (such as lower anxiety), and an improvement in risk-reducing behaviors. There is also an economic benefit to genetic counseling. According to a study published by ARUP Laboratories in 2014, genetic counselors working at a diagnostic laboratory revised 26% of the test orders over a 21-month period, leading to healthcare savings of nearly \$1.2 million. With an adequate number of trained genetic counselors providing these services, additional decreased costs may continue to be realized by the health care system. Genetic counselors help to reduce the number of unnecessary and costly genetic tests ordered, by working as part of a healthcare team to appropriately assess which test is the most appropriate. They are also specially trained to discuss the risks, benefits, and limitations of genetic testing with the patients. Genetic counselors ensure that appropriate informed consent is obtained for all testing, a value that is upheld by New York State law.



Licensing creates clear educational, certification, and continuing education standards for all genetic counselors in the state. With licensing, unqualified practitioners can no longer claim to call themselves genetic counselors, thus the public will be protected. It is for these reasons and more that we urge you to SUPPORT the above legislation to license genetic counselors in New York State.



Sincerely,

Karen L. Ball

Karen L. Ball
Founder and CEO

