

February 21, 2023

AECS Applauds National Society of Genetic Counselors on Practice Guideline on Expanded Carrier Screening for Reproductive Risk Assessment

The Access to Equitable Carrier Screening Coalition (AECS), a multi-stakeholder coalition of laboratories, patients and providers dedicated to ensuring that individuals of reproductive age and their partners have access to equitable carrier screening, supports the National Society of Genetic Counselors (NSGC) Practice Guideline on expanded carrier screening.

With this new, evidence-based Practice Guideline, NSGC joins a growing number of voices acknowledging that advancements in carrier screening enable individuals to understand their reproductive risks in a more equitable manner and make informed decisions based upon their personal values and preferences.

NSGC's Practice Guideline, based upon a systematic evidence review, concludes that expanded carrier screening (ECS) provides a more equitable approach to carrier screening. In the Practice Guideline, NSGC recommends that "ECS be made available for all individuals considering reproduction and all pregnant reproductive pairs, as ECS presents an ethnicity-based carrier screening alternative which does not rely on race-based medicine." In addition, they conclude that that "ECS is superior compared to ethnicity-based carrier screening."

Haywood Brown, MD, board certified obstetrician and gynecologist and AECS Coalition Executive Medical Director, said, "NSGC's Practice Guideline is a crucial update in ensuring more equitable carrier screening practices. By encouraging the elimination of race or ethnicity-based medical decisions, NSGC is helping to address some of the systemic barriers that have historically prevented access to important reproductive planning information for certain individuals who do not fit into socially defined constructs of risk."

Teonna Woolford, Co-Founder and Chief Executive Officer of Sickle Cell Reproductive Health Education Directive, said, "This new guidance from NSGC plays an important role in providing information that all individuals and families should have before conceiving." Woolford, who was born with a rare disease and its many side effects, said, "Given my experience, it is part of my mission to ensure families have access to carrier screening." Woolford added, "Offering

carrier screening regardless of a person's race or ethnicity addresses previous limitations associated with ethnicity-based screening and identifies more affected pregnancies."

With this evidence-based guidance, in line with other professional societies, AECS looks forward to continuing our work to expand access to ECS by building relationships and partnerships with key stakeholders, facilitating information sharing about ECS, and collaborating with payers to ensure ECS coverage.

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