**STATEMENT**

**New Analysis Reveals Increased Access to Carrier Screening for Nearly 50M Individuals**

June 2, 2022

The Access to Equitable Carrier Screening Coalition (AECS) estimates that 49.6 million individuals now have equitable carrier screening coverage because multiple federal and private health payers recently updated their policies to include expanded carrier screening as a medically necessary service that an individual can choose to receive.

AECS, a multi-stakeholder coalition dedicated to ensuring that women of childbearing age and their partners have access to appropriate pan-ethnic and equitable carrier screening, performed an independent analysis to determine these results.

These payer updates follow the American College of Medical Genetics and Genomics (ACMG) October 2021 publication of their Practice Resource entitled “Screening for autosomal recessive and X-linked conditions during pregnancy and preconception,” which provides guidance on “a consistent and equitable approach for offering carrier screening to all individuals” and supersedes previous ACMG carrier screening recommendations. To effectuate a more equitable approach to carrier screening, ACMG now recommends that all pregnant patients and those planning on pregnancy should be offered carrier screening for >100 serious inheritable conditions.

Carrier screening is conducted to determine if individuals who are pregnant, or are planning to become pregnant, and their partner have the potential for passing a prevalent or serious childhood onset genetic condition to their child. Historically, carrier screening coverage has been based primarily on family history or ancestry. With recent updates in carrier screening technology, patients can now undergo screening for multiple conditions simultaneously.

This technology now enables a more equitable approach to carrier screening, which has become increasingly important as the United States population becomes more diverse. Limiting screening coverage to single-gene, ancestry-based testing results in failure to identify up to 77 percent of carriers.

Shari Ungerleider, Project Coordinator for the Jewish Genetic Disease Consortium (JGDC), said, “My oldest child, Evan, passed away from Tay-Sachs disease when he was 4 ½ years old. For many families like mine, carrier screening could have life-altering benefits.” Ungerleider added, carrier screening “could have helped my husband and I understand the options available to us for family planning and allowed us to make an educated decision based on accurate genetic information.”

“Payers are recognizing the need for a more equitable approach to carrier screening and are modernizing their policies to reflect the diversity of our country,” said Dr. Haywood Brown, board certified obstetrician and gynecologist and AECS Coalition Executive Medical Director. These payer actions were driven, said Dr. Brown, by “the important work of the clinician community, most notably the American College of Medical Genetics and Genomics (ACMG) and the American College of Obstetricians and Gynecologists (ACOG).”

*AECS works to promote and enhance access to pan-ethnic carrier screening by building relationships and partnerships with patient and provider groups, facilitating information sharing about pan-ethnic carrier screening, and collaborating with payers to ensure coverage of ECS.*