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Committee on Adolescent Health Care

The North American Society for Pediatric and Adolescent Gynecology endorses this document. This Committee Opinion was developed by the American College of Obstetricians and Gynecologists’ Committee on Adolescent Health Care in collaboration with committee members Meredith Loveless, MD and Kimberly Hoover, MD.

Genetic Syndromes and Gynecologic Implications in Adolescents

ABSTRACT: As adolescents with a genetic syndrome transition to adult medical care, they may be referred to obstetrician–gynecologists for routine preventive or contraceptive services, screening, or counseling for sexually transmitted infection, or for menstrual management. Although some genetic syndromes have no physical or intellectual impairment, others have significant ones; therefore, education and gynecologic care should be based on a patient’s intellectual and physical capabilities. It is important to remember that adolescents with or without a genetic syndrome are sexual beings. Thus, education about reproductive health, expectations for fertility, and healthy relationships is important when treating patients with genetic syndromes. Obstetrician–gynecologists must respect patient autonomy and avoid coercion in any discussions with a patient, including decisions about contraceptive choices, sexual activity, and pregnancy planning. Most patients who have genetic syndromes and are neurotypical can tolerate routine gynecologic examinations in the office, when necessary. A patient should not be forced to have an examination or be restrained for an examination. Obstetric care of adolescents and women with genetic syndromes can pose challenges and often requires a multidisciplinary approach from the time pregnancy is contemplated through the postpartum period. When caring for an adolescent with a genetic syndrome, individual patient and guardian concerns, medical diagnoses associated with the specific genetic syndromes, and medication interactions should be considered. Obstetrician–gynecologists are encouraged to seek out additional resources and expertise when caring for adolescents with underlying genetic syndromes.

Recommendations and Conclusions

The American College of Obstetricians and Gynecologists offers the following recommendations and conclusions:

- Obstetrician–gynecologists are encouraged to seek out additional resources and expertise when caring for adolescents with underlying genetic syndromes.
- Although some genetic syndromes have no physical or intellectual impairment, others have significant ones; therefore, education and gynecologic care should be based on a patient’s intellectual and physical capabilities.
- Obstetrician–gynecologists must respect patient autonomy and avoid coercion in any discussions with a patient, including decisions about contraceptive choices, sexual activity, and pregnancy planning.
Patients with an underlying genetic syndrome should be offered age-appropriate gynecologic screening and human papillomavirus vaccination.

When an examination is necessary but not urgent for a patient who cannot tolerate in-office examination, the obstetrician–gynecologist should attempt to coordinate the examination with other procedures that require sedation, such as dental work.

Obstetrician–gynecologists should be aware of any unique surgical or anesthesia risk associated with the adolescent’s genetic syndrome.