OVERVIEW
This case involves a patient carrying the Huntington’s Disease gene who learns she is pregnant. This scene is representative of a scenario in an OB/Gyn patient encounter. Multiple religious, ethical and cultural issues underlie this scene so the case is relevant for use in undergraduate and graduate medical education. The video highlights situations involving genetic testing, reactions to genetic test findings and partners with differing views but is presented to allow faculty the opportunity to discuss other issues not uncommon to the reproductive clinic. This video also allows future healthcare providers to address personal biases, such as caring for patients with heavy tattooing, that should not influence patient interactions. The physician’s handling of the situation is also portrayed to allow discussion of professionally managing patient encounters.

Learning Objectives
At the end of the session, the student should be able to:

1. Recognize the ethical issues surrounding prenatal genetic testing.
2. Recognize the common emotional reactions associated with genetic testing outcomes.
3. Discuss the role of the obstetrician-gynecologist when ordering genetic testing.
4. Develop strategies for providing healthcare to patients adapting to genetic test findings.

Critical Points (Every Student Needs to Hear)
- Pregnant patients who carry genes predisposing them or their children to genetic diseases, patients who are considering pregnancy and are at risk for giving birth to affected children, and gynecology patients who may have inherited a mutant Huntingtin gene are all candidates for prenatal genetic testing (ACOG Committee Opinion, Number 410, 2008).
- Patients who are found to be carriers of the Huntington’s Disease and their families (as well as those with other inherited disorders) should be offered counseling and follow-up (ACOG Committee Opinion, Number 410, 2008).
- Genetic testing provides information that affects the patient, as well as their biological relatives. Generally, practitioners should recommend that patients voluntarily share relevant genetic information with affected family members when appropriate (ACOG Committee Opinion, Number 410, 2008).
- Obligation to disclose genetic testing results to affected family members has been considered in the courts in several states. Clinicians should be familiar with court rulings about patient duty and duty to inform family members in the state they practice in.

Background Information
- Huntington’s Disease is a progressive neuropsychiatric condition that results from an expansion of a duplication in the DNA sequence termed CAG (cytosine-adenine-guanine) in the Huntingtin gene (HTT gene) on chromosome 4 (Andersson, Juth, Petersén, Graff and Edberg, 2012; Hoskins, Tita, Biggio and Ramsey, 2008). The hereditary disease is autosomal dominant, meaning a child can inherit the disease from only one parent (50% risk of inheriting the mutant gene).
- The most common form of Huntington’s Disease is adult onset usually presenting during a person’s thirties or forties, (https://ghr.nlm.nih.gov/condition/huntington-disease, accessed on July 9, 2016).
Background Information (Cont.)

- Patients with adult onset of Huntington’s Disease usually have a lifespan of 15-20 years once the disorder presents. The disease is characterized by worsening muscle dysfunction, personality changes and cognitive dysfunction (https://ghr.nlm.nih.gov/condition/huntington-disease, accessed on July 9, 2016).
- Practitioners need to be aware that genetic information about patients or their fetuses has significant implications for patients and their families. Release of genetic information has the risk of resulting in discrimination against patients or their family members by insurance companies or employers. Confidentiality must be assiduously guarded.
- Termination of pregnancies based on the results of prenatal genetic testing results is ethically controversial.

Questions to Ask

- How should the healthcare team proceed?
- What questions should the healthcare team/provider ask this patient?
- What priorities exist for this physician during this office visit?
- What members of the healthcare team would be essential to this case?

Concluding the Session

- Knowing you carry the Huntington’s Disease gene is traumatic. Finding out you are pregnant only increases the distress. Prior to making any decisions, a pregnant woman carrying Huntington’s Disease gene might wish to test the fetus for the gene or she may not want to take any action. The physician needs to provide accurate information as they educate the patient and discuss options. To provide the best possible patient care, physicians should offer support of other specialized healthcare providers, especially genetic counselors, as well as, social workers, therapists and clergy.

Reading Resources