NEWSLETTER

This newsletter centers on reproductive topics with a genetics focus. If there is an organization or upcoming webinar you'd like me to include in a future newsletter, please feel free to reach out at genetics@modernreproduction.org.

Sign up for the newsletter here

Webinars

PROGENESIS: A DEEP DIVE INTO PROGENESIS'S TEST-NIMA & WHOLE GENOME SEQUENCING

2/21 6PM EST

Register

ASRM:MENTAL HEALTH DIAGNOSES AND GAMETE DONOR SUITABILITY: MULTIDISCIPLINARY PERSPECTIVES AND INSIGHTS

2/20 4PM EST

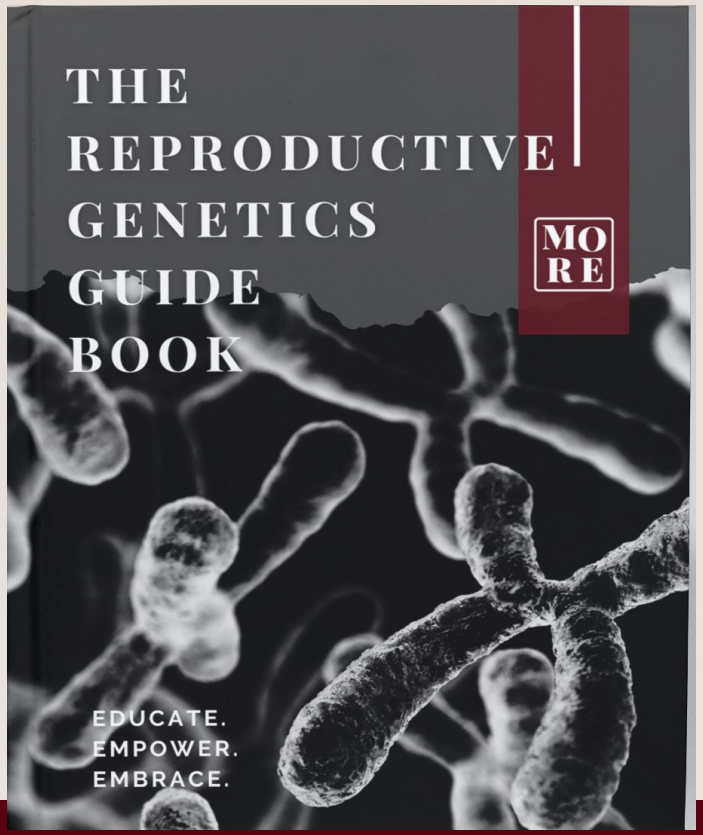
Register

NEWSLETTER

We're back!

Throughout the last few months, instead of putting out a weekly newsletter, *The Reproductive Genetics Guidebook* was being updated with the latest guidelines, articles, and topics.

For those that purchase the Guidebook, they are given the updated version at no cost as this is the whole point of Modern Reproduction - to have the latest information on reproductive genetic testing! For those interested in a copy, check out this link.



ISSUE 26

NEWSLETTER

The little lit review

1 Pregnant women's informational needs prior to decisions about prenatal diagnosis for chromosomal anomalies-A Q methodological study

Ellen Ternby, Ove Axelsson, Susanne Georgsson, Charlotta Ingvoldstad Malmgren

The article is from the perspective of Swedish pregnant people, who are typically offered diagnostic testing and cell-free DNA screening if their initial screening is position. Initial screening includes first trimester ultrasound and biochemical assessment. Since having higher knowledge about prenatal diagnosis seems to result in less decisional conflict, regret, anxiety and increases overall well being, this study investigates the type of information requested by patients.

The study found three factors contributing to information needs. Ultimately, the study concludes that individuals have various needs for information and individualized conversations are necessary to ensure patients receive the amount and type of information most helpful to make decisions with.

Factor 1:
See information and decision-making as a step-by-step process, where step 1 is focused on information and decision-making regarding PND. Information about conditions screened for is desired in step 2, if screening indicates an increased probability for an anomaly. They do not want too much information on a single occasion or too early in the pregnancy.

Factor 2:
Strive for an informed decision together with their partner regarding the complete concept of accepting or declining screening and how to handle the test result. Prefer written information over verbal.

Factor 3:
Want to get as much information as possible, as early as possible.

"The[re is] need to better educate healthcare professionals if the needs of pregnant women are to be met."

"Receiving updated, fact-based information from a **knowledgeable** healthcare professional was highly prioritized from all three viewpoints."

NEWSLETTER

The little lit review

Knowledge gaps and confidence in counseling about aneuploidy screening and testing: A survey of prenatal care clinicians

M M Thorsen, K Khanuja, R C Mahoney, H B Al-Kouatly, M L Russo

The last article found that patients prioritize a healthcare provider who is knowledgeable about the tests they are offering and the corresponding conditions that are being evaluated. This study evaluates providers' knowledge of testing.

"Of all respondents, 39% (39/100) were confident or extremely confident in their ability to counsel based on ACOG recommendations. However, of those confident or extremely confident respondents, the majority, 59% (16/39) were not able to answer all four ACOG knowledge questions accurately."

Education for both patient and providers are important given the nuances and constantly evolving landscape of genetic tests. Some providers spontaneously requested education tools for themselves as well as educational tools for patients. Ideally, patients are given foundational information on testing options prior to their appointments, so providers, who on average spend 5.6 minutes counseling, can focus on patient tailored decision making.

CLINICIAN QUESTIONNAIRE WITH CORRESPONDING CORRECT ANSWERS IF APPLICABLE

1. Chromosomal abnormalities occur in 1/300 live births.
   [X] True
   [ ] False
   [ ] Unsure
2. ACOG recommends offering diagnostic testing (amniocentesis or chorionic villus sampling) to high-risk pregnant women, but not all women.
   [ ] True
   [X] False
   [ ] Unsure
3. A screening test can predict risk, but it cannot make a diagnosis.
   [X] True
   [ ] False
   [ ] Unsure
4. ACOG recommends that all patients are counseled on the concept of residual risk after a low screening result.
   [X] True
   [ ] False
   [ ] Unsure
5. When a patient decides to have cell free DNA, their data may be kept for an indefinite amount of time for research by the company running the test.
   [X] True
   [ ] False
   [ ] Unsure

When providing patients with prenatal genetic counselling, how confident are you in your ability:

6. To counsel based on ACOG recommendations
   [ ] Not confident at all
   [ ] Somewhat confident
   [ ] Confident
   [ ] Extremely confident
7. To answer patient questions re: cost of testing
   [ ] Not confident at all
   [ ] Somewhat confident
   [ ] Confident
   [ ] Extremely confident
8. To answer patient questions re: privacy of their genetic results[ ] Not confident at all
   [ ] Somewhat confident
   [ ] Confident
   [ ] Extremely confident
9. How many minutes do you typically spend counselling on prenatal genetic testing: _[*drop down menu with numeric values 0–50*]
10. How do you feel about the amount of time you typically spend counselling patients on prenatal genetic testing:
    [ ] Far to little time
    [ ] Too little time
    [ ] About the right about of time
    [ ] Too much time
    [ ] Far too much time
11. Please select any/all barriers you perceive in your practice to providing patients with adequate counselling on prenatal genetic testing:
    [ ] Language barriers
    [ ] Health literacy
    [ ] Lack of visual aid
    [ ] Time constraints
    [ ] Knowing what ACOG's recommendations are re: what testing should be offered
    [ ] Knowing what testing is covered by insurance
    [ ] Knowing how patient privacy is or is not protected
    [ ] My personal beliefs about genetic testing
    [ ] Other __
12. What would be your hope/wishes for an educational tool for patients surrounding prenatal genetic testing:
    _ [*free response*]

Demographics:

13. With which of the following groups do you identify:
    [ ] Advanced Practice Provider
    [ ] Resident Physician in Ob/Gyn
    [ ] Maternal Fetal Medicine Specialist
    [ ] General Ob/Gyn Attending Physician
14. How many years have you been in obstetrics practice?
    [*drop down menu with numeric values 1–50]*

NEWSLETTER

What else have we been doing?

Substack :D

The move to publish on Substack is to further conversations on the ethical and social impact reproductive medicine has on our society - not just in the states but globally. While we have studies that assess patient desires, there are less society at large discussions, until something goes awry. I've subscribed to the Progress Education Trust's BioNews to learn of instances of concern. Check out the Substack and let's chat :)

Community Content:

PET
Fertility • Genomics • Clarity