



2019 Annual Meeting & Conference

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Healthy Mothers, Healthy Babies. In That Order.
Centering Mother's Voices in Maternal Care.



WHAT FAMILIES SHOULD ASK DURING A HIGH-RISK PREGNANCY...

AND HOW TO RELAY
THE INFORMATION TO
THEM



COMPLICATIONS

- 6-8% of all pregnancies in the US are characterized as high risk
- 94% of pregnancies report experiencing complications
- The leading causes of high-risk pregnancies include preeclampsia, gestational diabetes, and fetal syndromes
- Birth defects are the leading cause of infant deaths, accounting for 20%
- 17-24 weeks' gestation when a fetal syndrome is detected
- Over 4,000 known fetal syndromes today

FETAL SYNDROMES + OCCURRENCES

1 / 3,000-5,000
live births

- Congenital Diaphragmatic Hernia - babies need to be monitored and delivered at a specialized treatment center; often unable to breathe on their own when born.

1 / 1,500-4,000
live births

- Fetal Hydrops - treatment varies, as fetal hydrops is associated with several underlying causes; between 60 and 90% of babies diagnosed die before birth.

1 / 4,344 live
births

- Hypoplastic Left Heart Syndrome (HLHS) - left untreated, babies born with this disorder die in the first few weeks of life.

1 / 5,000-7,000
live births

- Lower Urinary Tract Obstruction (LUTO) - depending on the severity, the mortality rate for babies with LUTO who do not receive treatment can be as high as 77%.

FETAL SYNDROMES + OCCURRENCES CONTD.

1 / 35,000-40,000
live births

- Sacrococcygeal Teratomas - requires complete surgical resection before/after birth, and generally shows positive outcomes. Large teratomas can cause life-threatening complications for both the fetus and the mother.

10-15% of twins
(shared placenta)

- Selective Intrauterine Growth Restriction (SIUGR) - without intervention, the mortality rate of at least one twin prior to birth is 40%.

1 / 35,000 live
births

- Twin Reversed Arterial Perfusion Sequence (TRAPS) - left untreated, one twin will most likely die prior to birth and the second twin has a 50% chance of survival.

1-3 / 10,000
live births

- Twin-to-Twin Transfusion Syndrome (TTTS) - left untreated, the survival rate is 10-15%.



A HIGH-RISK PREGNANCY DIAGNOSIS: NOW WHAT?

Photographee.eu, Stock ID: 300641399 (2015). *Crying married couple sitting at doctor's office.* Purchased from Shutterstock.com.

GENERAL UNDERSTANDING

- Why are they high risk? Age? Results from a scan or test? Current health concerns or genetic markers? Multiple birth pregnancy? Fetal syndrome diagnosis?
- Patient families absorb very little information after the diagnosis
- Provide information and resources for support (i.e. the Fetal Health Foundation www.fetalhealthfoundation.org)
- Keep it simple --- the clinical version leads to confusion and most won't know the questions to ask for clarification
- Plan a follow-up call/visit to answer questions and discuss the plan for moving forward

QUESTIONS FOR WHICH TO PREPARE

- Is this my fault? Did I do anything to cause this?
- What can you tell me about my fetal syndrome?
- Is there treatment available and will insurance cover the treatment?
- Will my baby(ies) have a chance to live?
- Is bedrest or inpatient care possible or recommended?
- Can I go back to work?
- What type of monitoring will I need? Will I be seen by a specialist? What can I do for my baby(ies) in between appointments?
- Will my baby(ies) be born prematurely?
- What is the likelihood of a NICU stay?
- How may my birth/delivery plan be altered?
- Are there area supports for parents like us?

NEXT STEPS

- Connect with an area specialist
- Review patient files for treatment plan
- Refer patient family to Fetal Health Foundation and other support groups/agencies (note – this never replaces medical information --- everyone's journey will be different)
- Familiarize with other patient families who may be willing to share their experience

WORKS CITED

- Center for Disease Control;
<https://www.cdc.gov/ncbddd/birthdefects/data.html>
- Merck Manual, Consumer Version;
<https://www.merckmanuals.com/home/women-s-health-issues/high-risk-pregnancy/overview-of-high-risk-pregnancy>
- Mayo Clinic; <https://www.mayoclinic.org/healthy-lifestyle/pregnancy-week-by-week/in-depth/high-risk-pregnancy/art-20047012>
- Fetal Health Foundation; www.fetalhealthfoundation.org;
<https://www.fetalhealthfoundation.org/fetal-syndromes/>