



of all pregnancies in the US are characterized as high risk, meaning that there is a serious anomaly that may affect the life of the mother or baby during pregnancy

94%

of all pregnancies report experiencing some type of complication

200

babies die each day as a result of a fetal syndrome

17-24

weeks' gestation is when fetal syndromes are generally detected



Each summer, millions of expectant parents celebrate the imminent arrival of their new family members with baby showers and parties. In fact, nearly 4 million babies were born in the United States in 2017, the most recent year for which the CDC has published data. Unfortunately, the joy that expectant parents feel is often tampered by medical complications and concerns.

# **Pregnancy complications**

The leading causes of high risk pregnancies include preeclampsia, gestational diabetes, and fetal syndromes. More than 800,000 pregnancies are affected by a fetal syndrome each year. The majority of fetal syndromes have no known cause.

## Fetal health syndromes

There are 4,000 known birth defects and the causes are largely unknown. Some of the most common fetal syndromes include:

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%.

1 / 35,000-40,000 live births Sacrococygeal 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%.



The Fetal Health
Foundation provides
a range of support for
families when their
unborn children are
diagnosed with a fetal
condition.

We're happy to recommend and put you in touch with a maternal-fetal medical expert specializing in any fetal condition or to connect you with a family who has experienced a fetal syndrome.

## **CONTACT:**

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### **Maternal Fetal Care Centers**

While most babies are delivered and receive the necessary care in the maternity ward at a local hospital, babies that are diagnosed with a fetal health syndrome require special care. Maternal Fetal Care Centers provide specialized and coordinated care for both mother and baby before, during and after complicated pregnancies. Typically, these centers are staffed by a team of specialists including:

- Neonatologists: doctors with expertise caring for newborns with birth defects or complications associated with prematurity
- Maternal-fetal medicine (MFM) specialists: obstetrician/gynecologists with additional training in maternal and fetal complications of pregnancy
- · Board-certified pediatric medical and surgical sub-specialists

Additionally, Maternal Fetal Care Centers have specialized equipment and tools that allow them to treat fetal heath syndromes in a variety of ways, depending on the diagnosis and severity of the individual case, including but not limited to:

- Expectant Management (frequent ultrasound assessments)
- · Interventional medications
- Amniocentesis
- Open fetal and minimally invasive surgery

#### **Fetal Surgery**

Fetal surgery is a highly complex surgical intervention to repair birth defects while babies are still in the womb. It allows doctors to treat serious and life-threatening conditions and stop progressive damage, while also keeping the baby in utero long enough to grow and develop.

The first successful human fetal surgery case was performed in 1981 at the University of California, San Francisco. Since then, more than 5,000 fetal surgeries have been performed worldwide and new procedures are being developed annually. Today, fetal therapy is recognized as one of the most promising fields in pediatric medicine, and prenatal surgery is becoming an option for a growing number of babies with birth defects.

