TRISOMY 18 foundation

Understanding Trisomy 18

A Guide for Newly Diagnosed Families

Learning that your child has a diagnosis of **Trisomy 18** can feel overwhelming. You may be facing an uncertain future and many questions. Most parents have never heard of Trisomy 18 before receiving a diagnosis.

While medically considered rare, **Trisomy 18 affects about 1 in every 2,000 pregnancies in the United States**. You and your child are not alone.

The Trisomy 18 Foundation provides trusted information, resources, and connections to other families who understand this journey so you can make informed decisions about your child's care.

What is Trisomy 18?

Trisomy 18, also called Edwards syndrome, is a genetic condition that occurs when a baby has three copies of chromosome 18 instead of the usual two.

Chromosomes carry genetic information that guides development. The extra chromosome affects how a baby's body and organs develop before and after birth.

KEY FACTS

Trisomy 18 occurs in about **1 in 2,000 pregnancies**

Many babies require care in a **Neonatal Intensive Care Unit (NICU)** after birth

About **1 in 6,000 babies are born alive with Trisomy 18**

Children with Trisomy 18 experience a wide range of medical and developmental differences. Some are medically fragile, while others reach milestones, attend school, and enjoy meaningful time with their families. Every child's journey is unique.

Types of Trisomy 18

There are three main forms of Trisomy 18.

FULL TRISOMY 18	The most common type. The extra chromosome appears in every cell of the body.
MOSAIC TRISOMY 18	The extra chromosome is present in some cells but not others.
PARTIAL TRISOMY 18	A rare form where only part of an extra chromosome is present.

Common Medical Characteristics

Children with Trisomy 18 may experience a range of medical conditions, including:

Congenital heart defects	**Growth delays**	**Kidney differences**
Feeding and digestive challenges	**Developmental delays**	**Clenched hands or rocker-bottom feet**

The severity and combination of these conditions vary widely from child to child.

How is Trisomy 18 Diagnosed?

A diagnosis is confirmed by examining a baby's chromosomes through a test called a **karyotype**. Testing may occur during pregnancy (prenatal) or after birth.

SCREENING TESTS

Screening tests estimate the likelihood of Trisomy 18 but **cannot confirm a diagnosis.**

Examples include:

- Noninvasive Prenatal Testing (NIPT)
- Maternal blood screening (quad screen)
- Ultrasound imaging

DIAGNOSTICS TESTS

Diagnostic tests analyze a baby's actual cells and **can confirm Trisomy 18.**

Examples include:

- Chorionic Villus Sampling (CVS)
- Amniocentesis

Understanding which test was performed is important as families consider next steps and care decisions.

You Are Not Alone

Families navigating a Trisomy 18 diagnosis often feel isolated at first. The Trisomy 18 Foundation exists to ensure no family faces this journey alone.

We provide:

- Newly diagnosed family resources
- Parent support connections
- Community and advocacy resources

Every life deserves *dignity.* **Every family deserves** *support.* **Every step deserves** *resources.*

LEARN MORE & FIND SUPPORT

Explore resources and connect with other families at
www.trisomy18.org

T18F foundation