TRISOMY 18

New and Expectant Parent Resource Guide

Prepared by the Support Organization for Trisomy 18, 13, and Related Disorders

WELCOME & SUPPORT

Receiving a trisomy diagnosis can be overwhelming, but you are not alone. The Support Organization for Trisomy 18, 13, and Related Disorders (SOFT) offers a compassionate community of parents, families, healthcare providers, and supporters. SOFT provides resources, shared experiences, and a listening ear to help you navigate this journey with hope and confidence.

Supportive Network	Connect with families and professionals who understand trisomy diagnoses.
Information & Resources	Access up-to-date information on Trisomy 18, 13, and related disorders.
Empowerment	Guidance to help families advocate for their needs and make informed decisions.

WHAT IS TRISOMY 18?

TRISOMY 18 is caused by an extra copy of chromosome 18, occurring in about 1 in 6,000 live births. It is also called Edwards syndrome. It is also called Edwards syndrome, named after the British geneticist who first described it in 1960.

Full trisomy	Extra chromosome 18 in every cell — 95% of cases
Mosaicism	Mix of typical and trisomy 18 cells — about 5%
Translocation	Extra piece of chromosome 18 attached to another chromosome

1 in 6,000	**13.5%**	**35–45%**
live births	survive to 1 year	survive past 1st month

HOW IS IT DIAGNOSED?

Screening	NIPS/NIPT blood test and fetal ultrasound from 10 weeks. These do NOT confirm a diagnosis.
Confirmed	Amniocentesis (after 15 weeks) or CVS (10–12 weeks). Both are highly accurate with very low added risk.

COMMON HEALTH CONSIDERATIONS

Heart (90%)	VSD, ASD, PDA are most common. About 1 in 6 children have more complex heart defects.
Breathing	Obstructive apnea, pulmonary hypertension, and feeding-related aspiration.
Feeding	Difficulty breast or bottle feeding is very common. NG or G-tubes may be needed.
Development	Delays are present in all children. Each child reaches milestones in their own time.
Other	Seizures (25–30%), kidney differences (50%), hearing, vision, and scoliosis.

"Every child with Trisomy 18 surprises us. Children thrive, smile, and love on their own terms."

YOUR CHOICES

Continue the pregnancy

Work with your OB or MFM on a tailored care plan for monitoring, delivery, and newborn care.

■ Planned intervention

Pursue medical and surgical interventions to support your baby's survival and quality of life.

■ Palliative / comfort care

Focus on bonding and comfort. Palliative care teams support families with compassion at every step.

■ Adoption

Families who specifically seek to adopt children with Trisomy 18 do exist.

Terminate the pregnancy

A legal option in many states. Laws vary rapidly. Your OB, MFM, or genetic counselor can provide safe options.

SPECIALISTS YOU MAY MEET DURING PREGNANCY

- Maternal Fetal Medicine (MFM) — high-risk OB
- Medical Geneticist / Genetic Counselor
- Neonatologist — newborn intensive care
- Pediatric Cardiologist — heart specialist
- Pediatric Cardiothoracic Surgeon — infant heart surgery
- Palliative Care Specialist
- Pediatric Surgeon — if surgery is planned
- Pediatrician — ongoing primary care

Child Development

Children with Trisomy 18 who grow into childhood can recognize family, smile, and learn. Many sit without assistance. Some crawl or walk with a walker. Some use words or AAC communication devices. Therapies and a loving environment make a real difference.

CONNECT WITH SOFT

SOFT Parent-to-Parent Support
Connect with a trained SOFT parent who has walked this path
trisomy.org/contact-us

Talking Trisomy Podcast
Expert interviews with clinicians and advocates — YouTube and Spotify
trisomy.org/talking-trisomy-podcast

FREQUENTLY ASKED QUESTIONS

Will my baby be born alive?

Outcomes vary widely. Some babies are stillborn or face immediate challenges. Others are born alive and go home, some thriving for months or years.

What happens in the delivery room?

You set goals with your care team ahead of time — from peaceful comfort care to full resuscitation. There is no single right answer.

Can we take our baby home?

Many families do. Care at home ranges from hospice to complex medical management. SOFT connects you with families who have navigated each path.

Should we pursue heart surgery?

An individualized decision with your cardiologist and surgeon. Research shows interventions can improve survival. Your values and goals guide it.

Will my baby ever walk or talk?

Some children learn to walk with support and use words or AAC devices. Milestones come on their own timeline with therapy and love.

SOFT & CLINICAL RESOURCES

Trisomy 18 New & Expectant Parent Book
Free — English and Spanish at trisomy.org
trisomy.org/expectant-parent

AAP Clinical Report: Trisomy 13 & 18 Care
American Academy of Pediatrics — July 2025
doi.org/10.1542/peds.2025-072719

National Organization of Rare Diseases
NORD Trisomy 18 Syndrome resource page
rarediseases.org

National Abortion Federation
Resources and support for abortion access and providers
nationalabortionfederation.org

Courageous Parents Network
Video library — Trisomy 18 palliative & family care resources
courageousparentsnetwork.org

A Time to Decide, A Time to Heal
For Parents Making Difficult Decisions About Babies They Love
Available on Amazon

The EWE Foundation
Supporting families of children with rare chromosome conditions
theewefoundation.org

Ready to connect?

Scan or visit trisomy.org/contact-us — a SOFT team member will reach out to walk alongside you.