TRISOMY 13

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 13, 18, and related disorders.
Empowerment	Guidance to help families advocate for their needs and make informed decisions.

WHAT IS TRISOMY 13?

TRISOMY 13 is caused by an extra copy of chromosome 13, occurring in about 1 in 10,000 to 25,000 live births. It is also called Patau syndrome, named after the geneticist who first described it in 1960.

Full trisomy	Extra chromosome 13 in every cell — about 90% of cases
Mosaicism	Mix of typical and trisomy 13 cells — small percentage of cases
Translocation	Part of chromosome 13 attached to another chromosome

1 in 10,000+	**11.5%**	**9.7%**
live births	survive to 1 year	survive to 5 years

HOW IS IT DIAGNOSED?

Screening	NIPS/NIPT blood test and fetal ultrasound. 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 (80%)	VSD, ASD, PDA, and dextrocardia are most common.
Brain/Head	Holoprosencephaly (60%), small head size (microcephaly).
Face	Cleft lip with or without cleft palate in about 60% of children.
Eyes	Eye abnormalities in over 50% of children, including small or absent eyes.
Feeding	Feeding difficulties, gastroesophageal reflux, and constipation are very common.
Development	Delays are present in all children. Each child reaches milestones in their own time.
Other	Seizures, kidney defects, hearing loss, scoliosis, sleep apnea, hypertension.

"Every child with Trisomy 13 is unique. With support, children grow, connect, and bring profound joy."

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 13 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 13 who grow into childhood can recognize family, respond to voices, and show emotion. Positive support, quality educational programs, stimulating environments, and therapies all lead to increased enrichment and a wide range of skills.

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 support to complex medical management. SOFT connects you with families who have navigated each path.

Should we pursue heart surgery?

Research shows cardiac interventions can improve survival. One study found a median survival of nearly 15 years post-discharge after cardiac surgery. Your values and your baby's situation guide the decision.

Will my baby ever walk or talk?

Some children with Trisomy 13 learn to communicate, respond to family, and develop meaningful skills. Every child progresses on their own timeline with therapy and love.

SOFT & CLINICAL RESOURCES

Trisomy 13 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 13 Syndrome resource page
rarediseases.org

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

Courageous Parents Network
Video library — Trisomy 13 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.