

A Guide to Finding Trisomy-Friendly Healthcare Teams



COMPASSIONATE CARE. ♥ INFORMED CHOICES. ♥ STRONGER TOGETHER.



*Your child.
Your voice.
Your journey.*



Families impacted by
Trisomy 18 deserve
compassionate, informed,
and supportive care.



This guide is designed to help
you identify healthcare teams
and facilities that honor your
child's life, respect your family's
values, and partner with you in
every step of the journey.



1 Start With Your Primary Care Provider

- Ask your pediatrician or family doctor if they have experience with Trisomy 18 or other rare chromosomal conditions.
- If not, ask whether they are open to learning, collaborating, and connecting with specialists.
- A supportive provider is often more important than one with "experience only."



2 Identify Key Specialists

Families often benefit from a multidisciplinary team. Commonly involved specialists include:

- **Genetics** – for diagnosis confirmation, care planning, and family guidance.
- **Cardiology** – as many children with Trisomy 18 have heart conditions.
- **Neurology** – for seizures or developmental concerns.
- **Pulmonology/ENT** – for breathing and feeding issues.
- **Gastroenterology/Nutrition** – for feeding support, G-tube management, growth.
- **Palliative Care** – not just end-of-life care, but quality-of-life support, symptom management, and coordination of care.



3 Look for "Trisomy-Friendly" Traits

- Respects your goals and values as a family.
- Avoids blanket assumptions about quality of life.
- Provides options, not ultimatums (e.g., presenting surgery, medical management, or comfort care as choices).
- Welcomes shared decision-making and ongoing dialogue.
- Connects you with other families, support groups, and resources.



4 Ask the Right Questions

When meeting a new provider, you can ask:

- Have you cared for children with Trisomy 18 (or similar conditions)?
- How do you approach treatment decisions for children with rare and life-limiting conditions?
- Do you partner with parents in care planning?
- How do you coordinate across specialties?
- Are you open to consulting guidelines from Trisomy advocacy groups?



5 Leverage Networks and Referrals

- Use hospital "complex care" or "pediatric palliative care" programs to connect with multidisciplinary teams.
- Consider teaching hospitals or children's hospitals, which are more likely to have genetics and specialized clinics.
- Ask other Trisomy families for recommendations.



6 Advocacy Tips When Facing Barriers

- **Bring documentation:** Carry medical summaries, care guidelines, and advocacy resources to appointments.
- **Request second opinions:** Don't hesitate to move on from a provider or facility unwilling to engage.
- **Document conversations:** Keep notes of discussions, decisions, and agreed plans.
- **Empower your voice:** Remember, you are the expert on your child.



Finding the right healthcare team for your child with Trisomy 18 can feel overwhelming, but you are not alone. The most important step is surrounding your family with providers who listen, respect your goals, and partner with you in care.

*You are not alone.
We are here.*

