

## Resources for Families

### Books:

Prenatal diagnosis and decision-making

“Time to Decide, Time to Heal: For parents making difficult decisions about babies they love”

“Gift of Time” – a gentle and practical guide for parents who are (or are considering) continuing their pregnancy knowing that their baby's life will be brief.

### Web-based

Trisomy 13/18 specific:

Hope for Trisomy - [www.hopefortrisomy13and18.org](http://www.hopefortrisomy13and18.org)

International Trisomy 13/18 Alliance - <http://www.internationaltrisomyalliance.com/>

The Chromosome 18 Registry and Research Society - <http://www.chromosome18.org/>

Facebook groups – search for Trisomy 13 or 18

Trisomy 13 LIFE LWT 13 (and many more)

Trisomy 18 Foundation (and many more)

Rare Trisomy Parents

"Care of the Infant and Child with Trisomy 18 or Trisomy 13" by Ann Barnes (available for free download at [trisomy.org](http://trisomy.org))

General support:

SOFT: Support Organization for Trisomies – [trisomy.org](http://trisomy.org)

NORD: National Organization for Rare Diseases - <http://rarediseases.org/>

First in Families of North Carolina - <http://www.fifnc.org/>

Courageous Parents Network - <https://courageousparentsnetwork.org>

Seattle Children’s Hospital Decision Making Tool for Families -  
[www.seattlechildrens.org/pdf/Decision\\_Making\\_Tool.pdf](http://www.seattlechildrens.org/pdf/Decision_Making_Tool.pdf)