

For Those Parenting a Child with Trisomy

♥ Managing your child's care



- [Care of the Infant and Child with Trisomy 18 or Trisomy 13, 4th edition; 2018, a free SOFT E-book by Barnes, Carey](#)

- [Video: EVERY CASE IS UNIQUE: Delivering optimal medical care to babies born with Trisomy 13 and Trisomy 18. Dr. Martin McCaffrey speaking at the Perinatal Conference in Dublin, 2016](#)

- [Constipation 101 – a video presentation about understanding constipation in children, hosted by Terre Krotzer at Trisomy Talk. Here is a transcript of the Constipation 101 video presentation.](#)

- [When in the Hospital](#) by Ann Barnes (life support orders & more)

- [Helpful Information](#) Equipment, medical/surgical info, Medicaid Waiver, legal aid, premie clothes & more.
- [About Palliative Care, Perinatal Palliative Care and Hospice](#) by Ann Barnes
- [Medical Care Issues: from The Complex Child e-magazine](#)
- [Medicaid, Katie Beckett, TEFRA, etc.](#)
- [Medicaid Waiver information by state](#)

♥ **Surgery and Growth**

- [Surgery Information and Growth Charts](#) (SOFT data)
- [Hope for Lilliana](#) (video about her cardiac surgery)
- [Congenital Heart Defect: corrective surgery](#) (link)



[The Complex Child E-Magazine](#) covers many subjects of interest to families

having children with chromosome conditions and has an extensive archive of past articles.

♥ **Other**

- [Workshop Summaries](#) (from past conferences)
- [Helpful Organizations](#)
- [Helpful Information](#)
- [Wills, Trusts, and Estates](#)
- [Glossary of Genetic and Medical Terminology](#)
- [Contact SOFT Headquarters](#)
- [U.S. & Canadian Chapter Chair Contacts](#)
- [Other Trisomy 18/13 Support Groups](#)
- [International Support Groups & Contacts](#)

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