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, preemie 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 Lilianna** (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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