Professional Literature: Ethics and Commentaries

In addition to the information listed here, some useful books are available from the SOFT publications page: *Trisomy 18: A Handbook for Families* and *Trisomy 13: A Handbook for Families*. These touch on legal and educational aspects as well as the diagnosis itself. Also available is *Care of the Infant and Child with Trisomy 18 or Trisomy 13* which provides a great deal of care information for families. All these are available in both English and Spanish.


♦ Video, McCaffrey, 2016: *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

♦ Bruns, D, et al, 2016  Twenty-Two Survivors over the Age of 1 Year with Full Trisomy 18: Presenting and Current Medical Conditions  American Journal of Medical Genetics, Part C, Seminars in Medical Genetics, September 15, 2016 (whole issue)


♦ Pearson, Alison, 05/06/2015  Never Say Never about our child  an article in the BMJ (formerly the British Medical Journal). In the latest of a monthly series in which patients and care-givers set the learning outcomes for readers, Alison Pearson asks healthcare staff to reconsider the concept of offering “false hope.”


♦ Koogler et al 2013 Hastings Center Report Lethal language, lethal decisions.  Although many of the congenital syndromes that used to be lethal no longer are, they are still routinely referred to as “lethal anomalies.”

♦ Berg et al. 2013 Am J Hosp Palliat Care., 2013,
Why were they in such a hurry to see her die?

Parents of a baby with trisomy 18 share the experience of their baby’s birth and short life including the lack of understanding of the staff. Both parents of the baby are physicians.


♦ Boss et al. 2013 Pediatrics Trisomy 18 and complex congenital heart disease: seeking the threshold benefit  A prenatal diagnosis of ductal-dependent, complex congenital heart disease was made in a fetus with trisomy 18. A prenatal ethics consultation was requested. Their journey to obtain approval before birth including multiple meetings with staff.

♦ Bruns, D. A. 2013.  Erring on the side of life: Children with rare trisomy conditions, medical interventions and quality of life. Journal of Genetic Disorders and Genetic Reports.  This article presents a call to examine the individual child rather than decision-making by diagnosis.

♦ Wu, et al. 2013  American Journal of Medical Genetics Part A Volume 161, Issue 10, Article first published online: 17 SEP 2013  Survival Rates, Times Noted for Live Births With Trisomy 13 and 18  Wu et al suggest that detailed and accurate information about the survival of children with trisomies 13 and 18 should be provided to parents,
genetic counselors, and health professionals caring for affected families.


♦ Heuser et al. 2012 J Med Ethics Survey of physicians’ approach to severe fetal anomalies. 732 members of the American Society of Maternal Fetal Medicine were surveyed regarding the manner in which women receiving a trisomy diagnosis are counselled, regarding termination and delivery.


Thiele et al, 2011. BMJ Destined to die An Australian mother’s experience: At 18 weeks’ gestation Pauline Thiele’s baby was diagnosed with trisomy 18, a usually lethal syndrome.

Everett BJ et al. 2011. J Clin Ethics Ethical care for infants with conditions not curable with intensive care. Offering intensive care to neonates who have conditions that carry extremely poor prognoses is a source of great contention amongst neonatologists.

Mercurio 2011 J Perinatol The role of pediatrics ethics committee in the newborn intensive care unit Two cases are presented as illustrations of pediatric ethics committee function.

♦ Morrison et al. 2010. Circulation *2010 American Heart Association Guidelines for Cardiopulmonary Resuscitation and Emergency Cardiovascular Care Science Part 3: Ethics* Healthcare professionals should consider ethical, legal, and cultural factors when caring for those in need of CPR.

♦ Wilkinson 2010 J Med Ethics *Antenatal diagnosis of trisomy 18, harm and parental choice.* This commentary assesses the possible harms of continued life, to a fetus with trisomy 18.

♦ McGraw et al. 2008. Pediatrics *Attitudes of neonatologists toward delivery room management of confirmed trisomy 18: potential factors influencing a changing dynamic.* Until recently, there was universal consensus that trisomy 18 was a lethal anomaly for which resuscitation in the delivery room was not indicated. There are two published responses to this article (Dr. S Showalter and Dr. John Carey):
  1. [https://pediatrics.aappublications.org/content/123/3/e548.long](https://pediatrics.aappublications.org/content/123/3/e548.long)
  2. [https://pediatrics.aappublications.org/content/123/3/e547.long](https://pediatrics.aappublications.org/content/123/3/e547.long)

♦ Siegel, 2006 Mt Sinai J Med *When staff and parents disagree: decision making for a baby with trisomy 13* Parents often make medical decisions
for their children. As pediatricians, we must be sure that the decisions are medically informed.