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 *“The Carebook”* which provides a great deal of care information for families. These are available in both English and Spanish.

Weaver, MS, et al, 2018  *Eliciting Narratives to Inform Care for Infants with Trisomy 18* Pediatrics, October 2018, Volume 142/Issue 4 Family Partnerships


Lorenz, et al, 2013 *Evolving Medical and Surgical Management of Infants with Trisomy 18*


Ethical Rounds: An infant with trisomy 18 and a ventricular septal defect Pediatrics, Volume 127, Number 4, April 2011. The case of an infant with trisomy 18 was presented to two neonatologists and an unrelated parent. They do not agree about the right thing to do.

Carey JC 2011. review of Janvier A et al 2011 Ethical Rounds: An infant with trisomy 18 and a ventricular


Muneuchi J. 2011. Cardiol Young Outcomes of cardiac surgery in trisomy 18 patients. The authors described 34 Japanese children with trisomy 18. Some of the children were treated conservatively while others had cardiac surgery. The one year survival rates for the two groups were 9% and 25%, respectively. The authors conclude that some children can be helped with cardiac surgery.

Kobayashi et al. 2010. Gen Thorac Cardiovasc Surg J, Radical surgery for a ventricular septal defect associated with trisomy. Five female infants with trisomy 18 from Japan underwent full cardiac repair. All survived surgery and lived beyond 30 days with an average survival after surgery of 815 days. The authors conclude that cardiac surgery can be beneficial for some children with trisomy 18.


Kaneko et al. 2008. Pediatrics Intensive cardiac
management in patients with trisomy 13 or trisomy 18

Am J Med Genet Part A. This article reviewed the outcome of 31 consecutive Japanese infants with trisomy 13 or 18 born between 2000 and 2005. Some children were offered both medications and surgery for cardiac anomalies resulting in a significant increase in survival.


Graham et al. 2004. Am J Cardiol Effectiveness of cardiac surgery in trisomies 13 and 18 (from the Pediatric Cardiac Care Consortium). A report of 35 cardiac surgeries performed at one of 48 reporting centers in the US, Canada and Europe.


Management of infants with large, unrepaired ventricular septal defects and respiratory infection requiring mechanical ventilation


defects – Survival studies – Oncology – Prenatal diagnosis