Professional Literature – Cardiac Surgery: Ethics and Management

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

**Domingo, L, Carey, JC, et al, 2018**  *Mortality and Resource Use Following Cardiac Interventions in Children with Trisomy 13 and Trisomy 18 and Congenital Heart Disease*  
https://doi.org/10.1007/s00246-018-2001-x

**Kosiv, KA, et al, 2017**  *Congenital Heart Surgery on in-Hospital Mortality in Trisomy 13 and 18*  
*Pediatrics*, November 2017, Volume 140/Issue 5

doi:

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


Janvier A et al 2011 Pediatrics 2011;127:754–759 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.


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.

Carey JC 2005. Health Supervision and Anticipatory
Guidance for Infants and Children with Trisomy 18 and
13 updated from 1993 Trisomy in Review, Trisomy 18,
13 and Related Disorders, Research Newsletter (SOFT)

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.

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

Effectiveness of cardiac surgery in trisomies 13 and
18 (from the Pediatric Cardiac Care Consortium). Am J

Carey JC 1993. Trisomy in Review, Trisomy 18, 13, and
Related Disorders, Research Newsletter Review of
history of partial trisomy 18 – Congenital heart
defects  – Survival studies  – Oncology  – Prenatal diagnosis