Professional Literature: Care Management and Social Issues

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 there is *Care of the Infant and Child with Trisomy 18 or Trisomy 13* which provides a great deal of care information for families. These are available in both English and Spanish.

♦ **Pyle, A.K., et al, 2018**  *Management Options and Parental Voice in the Treatment of trisomy 13 and 18*  *Journal of Perinatology*  A summary of current data and an ethical analysis of whether medical and surgical interventions should be offered to parents of newborns with trisomy 13 or 18.

♦ **Stanford Medicine News Center, 2017**  *Infants with the genetic disorders trisomy 13 or 18 are more likely to survive if they undergo heart surgery,* a study from researchers at Stanford and the University of Arkansas has found.

♦ **Kosho T, et al, 2016.**  *Does medical intervention*
affect outcome in infants with trisomy 18 or trisomy

♦ Satge D, et al, 2016  A Tumor Profile in Edwards
Syndrome (trisomy 18)  Am J Med Genet Part C Semin

♦ Satgé D, et al, 2017  A Tumor Profile in Patau
2017 May 25

♦ Acharya, K et al 2017  Major anomalies and birth-
weight influence NICU interventions and mortality in
infants with trisomy 13 or 18.  J Perinatol. 2017
Jan 12. doi: 10.1038/jp.2016.245. [Epub ahead of
print]

♦ 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

♦ Carey JC, et al 2016  Commentary on Perspectives
on the Care and Advances in the Management of
Children with Trisomy 13 and 18  American Journal of
Medical Genetics, Part C, Seminars in Medical
Genetics, September 15, 2016 (whole issue)

♦ Bruns, DA, 2016  The TRIS Project:  Tracking Rare
Incidence Syndromes.  An on-going project managed by
D.A. Bruns, PhD, at Southern Illinois University.  A
number of care, family experience and support
articles are listed on this link.  A link to
updated information is here.


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

Wu, et al 2013 Survival Rates, Times Noted for Live Births With Trisomy 13 and 18 It is suggested 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.


♦ Janvier A et al 2012. *The Experience of Families*
With Children With Trisomy 13 and 18 in Social Networks Am Academy of Pediatrics, doi:10.1542/peds.2012-0151


♦ Bruns D, Foerster K 2011. ‘We’ve been through it all together’: Support for parents with children with rare trisomy conditions. Journal of Intellectual Disability Research, 55(4), 361–369 abstract


♦ Romesberg TL 2008 Building a Case for Neonatal Palliative Care Neonatal Network: The Journal of


18 and Trisomy 13: II. Psychomotor Development